Exploring the Psychosocial Impact of Parental Mental Illness on Children: A Mixed-Methods Study in China

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Exploring the psychosocial impact of parental severe mental illness on children’s health: A mixed-methods study in China

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A Thesis Submitted to the Faculty of
The Harvard Medical School
in Partial Fulfillment of the Requirements
for the Degree of Master of Medical Sciences in Global Health Delivery
in the Department of Global Health and Social Medicine

Harvard University
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Abstract

Background: Children of parents with severe mental illness (COPSMI) are a substantial and marginalized population within society, especially in resource-limited settings. COPSMI experience a variety of adverse psychosocial outcomes and are at increased risk of developing their own mental illness. Appropriate preventative interventions can improve the psychosocial outcomes of such vulnerable children. While the last two decades have brought significant improvements in intervention programs, little is known about COPSMI in resource-limited settings, such as China.

Methods: This was a convergent mixed-methods study. A cross-sectional survey was conducted concurrently with qualitative in-depth interviews. 39 families [with one parent with severe mental illness (SMI), one child and one primary caregiver in each family] were participated in the quantitative assessment, and 17 parents with SMI, 13 children, and 15 primary caregivers completed individual interviews in the qualitative section.

Results: 1) Quantitative results: a) The average age of COPSMI was 12.7±3.3. Among 39 participant families, 32% SMI patients were primarily taken care of by their parents, and 36% children were primarily taken care of by their grandparents. b) Strength and Difficulty
Questionnaire (SDQ): COPSMI had different levels of difficulties according to child self-rated and caregiver-rated SDQ scores. Children self-rated total SDQ scores were 8.8±4.7, and caregiver-rated total SDQ scores were 8.2±4.7. 2) Qualitative results were organized under six thematic categories: a) The costs of SMI and children’s financial sacrifices; b) ‘Missing’ parents and self-supported children; c) Fragile families and cautious children; d) Children’s experiences of parental psychiatric symptoms; e) Stressed families and hopeless children; and f) Disclosure of parental mental illness and isolation.

Conclusions: While families are struggling with difficulties associated with mental illness, COPSMI in China are facing specific risks and need more support and protection. Chinese mental health professionals and social workers who work with adult mentally-ill patients need a better understanding of all aspects of psychosocial impacts of parental mental health problems on children’s health.

Key words: child, parental mental illness, psychosocial impact, mixed-methods study, China
Content

Part 1. Political economy and historical background ................................................................. 1
  1. Introduction .......................................................................................................................... 1
  2. Global Burden of Mental Illness ....................................................................................... 5
  3. Children of Parents with Severe Mental Illness (COPSMI) .................................................. 8
     3.1 Impact of parental mental illness on children’s health ....................................................... 8
     3.2 Intervention programs ..................................................................................................... 11
     3.3 Challenges ..................................................................................................................... 12
  4. Mental Health in China: History, actuality, challenges, and opportunities ....................... 14
     4.1 History of Health Care System ..................................................................................... 14
     4.2 Mental Health History in China .................................................................................... 17
     4.3 The National Mental Health Service Reform .................................................................. 18
     4.4 Challenges and Opportunities ..................................................................................... 22
  5. Conclusion .......................................................................................................................... 24

Part 2. One publishable research paper .................................................................................... 1
  1. Introduction .......................................................................................................................... 1
  2. Methods ............................................................................................................................... 4
     2.1 Participants ....................................................................................................................... 4
     2.2 Data Collection ................................................................................................................ 5
     2.3 Data Analysis .................................................................................................................. 5
     2.4 Ethical Statement ........................................................................................................... 6
  3. Results .................................................................................................................................. 7
     3.1 Quantitative results .......................................................................................................... 7
     3.2 Qualitative results ......................................................................................................... 9
  4. Discussion ............................................................................................................................. 15
  5. Limitations ........................................................................................................................... 19
  6. Conclusion ............................................................................................................................ 20
  7. References ............................................................................................................................ 21
Tables

Part 1. Political economy and historical background
Table 1: Basic socioeconomic and demographic indicators of China…………………………...14
Table 2: Health and epidemiologic indicators of China…………………………………………15
Table 3: Health system indicators of China……………………………………………………16
Table 4: Mental health indicators of China……………………………………………………21

Part 2. Publishable paper
Table 1: Demographic characteristics of parents with SMI……………………………………6
Table 2: Primary caregivers for SMI parents and their children………………………………….7
Table 5: Children and primary caregivers rated SDQ scores………………………………………8
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Part 1. Political economy and historical background

1. Introduction

Ziyi, the barefoot girl in the picture (1), lives in a small village in Henan province, China. With ropes tied around her neck and chest, this eight-year-old girl has been tethered to the vine in front of her grandparents’ household for over six years, until she was found by local media in September 2016. Her grandfather claimed that she became “dangerous” and attacked people after suffering serious fevers in 2010. Her father, who is handicapped, works in a factory in another town, while the location of her mother, who has suffered from severe mental illness, is unknown.

Her grandparents, who are both over 60 years old, are the sole caretakers of Ziyi and her two healthy younger brothers. Though the local government has provided the family with a low-income allowance, the old couple still cannot afford to send this poor girl to hospital for treatment. Her grandfather told the reporter, “She is dangerous to others. We can do nothing but tie her up here.” It was unknown where Ziyi, who does not go to school, slept at night. Whether she was untied and allowed to wash inside her grandparents’ home was not known either.
I read this story occasionally through the most popular Chinese microblogging website named ‘WeiBo’ (with a market penetration similar to Twitter) which has over 220 million subscribers and 100 million messages posted each day, when I started designing this project with my mentors and Chinese colleagues. Children whose parents suffer from severe mental illness have long been ignored not only by the public, but also by mental health professionals. When Ziyi’s story “went viral”, it seemed to be a favorable turn for such vulnerable children. Moreover, the next story should be considered as stronger evidence that these children have begun to attract much broader public attention in China.

Zhongwang (2), an 18 year-old boy graduated from Cangzhou, Hebei Province, scored 684 out of 750 points on China’s national college entrance examination. His score ranked the first in Cangzhou city where included over 30,000 graduates in 2017. He has been admitted to the department of computer science by Tsinghua University, one of the top universities in China, and the university will fund this optimistic and strong boy’s four years of tuition fees.

Zhongwang’s father, who has suffered from schizophrenia, can only do simple manual work. His mother’s lower limbs are disabled and must be taken care of by others. This family has
experienced extreme socioeconomic disadvantages. Zhongwang was diagnosed with congenital heart disease at 7 years-old. Though he recovered after a surgery, his already-poor family fell into even greater debt. He started to pick up garbage after school and sold what he found to earn money. Even during summer holidays, he occupied himself by teaching physics classes to earn living expenses for his first semester. He refused donations from the public because he did not want to owe others, “The most difficult time for me has passed, and I think I can live on my own right now.”

Children of parents with severe mental illness (COPSMI) are a substantial and marginalized population within society, especially in resource-limited settings. Although extensive evidence has shown their risks for adverse psychological outcomes, there has been little focus on such children’s subjective experiences and their understandings of parental mental illness (3). Therefore, this group of children is commonly known as “invisible children” (4).

Prevention is better than a cure. Appropriate preventative interventions can improve the psychosocial outcomes of such vulnerable children (5). While the last two decades have brought significant improvements in intervention programs (6, 7), two main weaknesses still exist in this field. First, we lack deep insights from the perspective of children due to lack of research. Second, little is known about this population in developing countries like China.

After implementing the nationwide mental health reform program in 2004, Chinese mental health professionals have been considering a prevention program focusing on COPSMI in order to prevent the transmission cycle of mental illness. Understanding children’s life experiences and the psychosocial impact of parental mental illness on children’s health lays a foundation for further improvement in health and quality of life for such children.
My project is a mixed-methods study of exploring the psychosocial impact of parental severe mental health on their children’s health. A mixed-methods research approach using a combination of quantitative and qualitative research methods can investigate this problem from different perspectives, which can help us obtain a holistic understanding of the general condition of such children in China. The overarching goal of this study was to add to the understanding of how parental severe mental illness could affect children from all kinds of aspects. The focus of this study was not only to elaborate potential sources of risks for such children, but to also identify sources of support and resilience.

My thesis is divided into three sections. The first section addresses the significance and the insufficient resources delivered to global burden of mental illness. The second section is a detailed description of what we have known about these children, and what can be done to support this vulnerable population. The third section is a historical systematic review of the resources, strategies, and problems of mental health services in the study setting.
2. Global Burden of Mental Illness

According to the World Health Organization (WHO), “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (8). In 2005, WHO European Ministerial Conference on Mental Health endorsed the statement “No health without mental health” (9), which spoke to the indispensible role of mental health in health care. The scale of the global impact of mental illness is substantial. Over 450 million people worldwide are currently suffering from mental illness, and one in four people will be affected by mental or neurological disorders at some point in their lifetime (10, 11). Mental illness has surpassed other non-communicable diseases and constitutes 13% of global burden of disease (12).

The magnitude of mental illness has been emphasized by studies on the global burden of disease. Severe mental illness (SMI), including schizophrenia (11\(^{th}\)) and bipolar disorder (17\(^{th}\)), appears in the top 20 causes of global burden of disease (13, 14). SMI was a major contributor of the growth of overall morbidity and disability worldwide. Nevertheless, the global burden of mental illness has been underestimated due to the inadequate consideration of the contribution of SMI from related causes (15).

However, in spite of the considerable burden and associated adverse economic and social effects, the treatment and care for people with mental illness which should be prioritized has so far been marginalized by policy makers globally (16). The health care resources allocated to mental health responding to the associated morbidity and distress are extremely low. People with mental illness are mainly neglected by the public and healthcare professionals. Pervasive stigma and discriminatory social structures contribute to the imbalance between the global burden of
disease attributable to mental illness, and the attention people with mental illness should receive (17, 18).

Many low- and middle-income countries (LIMCs) experience the highest burden of mental illness. Growing international evidence shows that mental illness and poverty interact in a negative cycle. Two principle causal pathways have been postulated to identify the mechanism for this cycle. According to the social causation hypothesis, poverty increase the risk of mental illness through heightening stress, increasing obstetric risks, decreasing social capital, social exclusion and violence (19). Conversely, according to the social selection hypothesis, people suffering from mental illness are at increased risk of remaining in poverty through reducing productivity, increasing health expenditure, and social stigma (20). In a recent systematic review, Lund et al. found over 70% studies in LMICs reported a positive association between a range of poverty indicators, including socio-economic status, social class, food security and financial stress, and common mental disorders (21).

The WHO Mental Health and Development report emphasized that people suffering from mental illness constitute a vulnerable population who need to be targeted for development assistance in LMICs (22). Mental and substance abuse disorders accounted for 26.8% of all years lived with a disability (YLDs) in LMICs (23). While nearly half of mentally-ill patients are living in LMICs, less than $2 per capita is spent on mental health care (24). The median number of mental health professionals is below one, and the median number of mental health beds per 100,000 population is below five (25).

The public health effect of SMI is comparative to that of many chronic physical illnesses which have received much more funding for treatment and related research (26). In LMICs, schizophrenia resulted in 14.4 million YLDs, which was more than YLDs caused by iron
deficiency anemia (27). Though without convincing evidence, there are reasonable grounds to believe that the situation has become worse as the burden of mental and substance abuse disorders increase. Though the significant economic and social cost of SMI has been well documented, and providing access to service for these conditions in LMICs are also appreciated, the service gap for SMI in most of resource-limited settings remains a major challenge.
3. Children of Parents with Severe Mental Illness (COPSMI)

3.1 Impact of parental mental illness on children’s health

Severe mental illness (SMI) is a broad category that includes the most disabling psychiatric disorders such as schizophrenia, bipolar disorder, delusional disorder, schizoaffective disorder and severe major depressive disorder. SMI brings a significant burden not only for patients alone, but also for the whole family (28). Relatives of these patients often experience burden, stigma and a deterioration of their own health (29). They have to face complex situations and multiple challenges. While their mentally-ill family members’ behavior have changed due to psychiatric symptoms, relatives are saddled with complete responsibility for their loved one’s care (30). Furthermore, mental health services are insufficient for the treatment of mentally-ill patients, family members bear an even greater burden (31).

In the past few decades, deinstitutionalization and community-based rehabilitation have increased the likelihood that patients with SMI who are also parents can raise their children on their own (32). The fertility rate among SMI women was estimated to be comparable to general population (33). Maybery et al. estimated in 2009 that 23.3% children were living with a parent with mental illness and 20.4% of mental health service users have dependent children in Australia, which suggested that one in five children were living in a family with a mentally-ill parent in Australia (34). O’Donnell et al. reported that the number of Australian children whose parents had a prior diagnosed mental disorder has been increasing at a rate of 3.7% per year from 1990 to 2005 (35). Empirical work suggested that at least 25% of adult patients who were admitted to UK inpatient settings had dependent children, and over half of patients with SMI were likely to live with a juvenile (36). A recently published epidemiological study reported that
a total of 2.7 million parents (3.8%) has a SMI and 12.8 million parents (18.2%) had any mental illness in the past year in US (37).

Since a significant number of children are exposed to parental psychopathology, researchers have begun to explore the impact of parental mental illness on offspring development and functioning. Mental disorders have long been considered as neurodevelopmental disorders. A person whose first-degree relatives are affected by mental illness are at six to eight times the risk of developing his or her own mental illness, compared with the general public. The first research on parental mental disorders and offspring psychological outcomes occurred in the 1980s, and mainly focused on the intergenerational transmission of psychopathology. In one of the first longitudinal studies (38), Beardslee and colleagues followed a group of children ages 6 to 19 over the course of four years. At the four-year follow-up, children of parents with a history of psychiatric disorders had higher rates of psychiatric diagnoses and poorer adaptive functioning than children of non-ill parents. Since that time, a large body of research has confirmed that children of parents with mental illness are at greater risk for psychiatric disorders compared to children of healthy parents.

The contribution of genetic factors, which was estimated to account for over 70% for schizophrenia and bipolar disorder, seems to be much higher than for common mental disorders (39). Children with one parent affected by schizophrenia have a 13% genetic risk of developing schizophrenia themselves, and the risk increases to 45% if both of their parents are affected by schizophrenia. Children of parents with bipolar disorder have a 7.8% risk of developing bipolar disorder themselves (40). Longitudinal studies have shown that the offspring of parents suffering from schizophrenia are at elective risk of developing not only schizophrenia-spectrum disorders, but also a range of different types of mental disorders (41). A recent systematic review which
included 33 family high-risk studies has reported that COPSMI had a one in three risk of developing SMI and one in two risk of developing any kind of mental disorders (42). The Helsinki High-Risk Study have reported that the cumulative incidences of any psychotic disorder were 10.0%, 4.0% and 1.1% among offspring of mothers with schizophrenia-spectrum disorders, affective disorders and health controls, respectively (43).

After the association between parental mental disorder and offspring psychopathology was confirmed and well documented in the literature, the focus of research turned to further impacts of parental mental illness on children. In addition to the higher risk of psychopathology, such children were also found to be at risk for a number of cognitive, social, and developmental problems. Results from the England Millennium Cohort Study, which assessed children in primary school, showed that children whose parents were experiencing higher level of psychological distress were more likely to have lower attainment in communication, language and literacy, mathematical development and personal, social and emotional development (44).

According to the mechanism of genotype-environment interaction, mental disorder tends to cluster in families not only because of a direct genetic effect, but also because relatives are more vulnerable to the risk-increasing effects of prevalent environmental risk factors (45, 46). A long-term follow-up study of adoptees which compared adopted-away offspring of mothers affected by SMI with adoptees without this genetic risk found that adoptive-family pattern was a significant predictor of the onset of SMI only in adoptees at high genetic risk (47). Living with a parent suffering from SMI causes a variety of detrimental social consequences for this vulnerable population (48), partially shown by the two anecdotes in the beginning.

International studies have identified a range of factors including genetic inheritance, psychosocial adversity, family relationships, the engagement of parents in a child’s life, as
important factors that influence children’s mental health (49, 50). Compared to those with healthy parents, COPSMI are more likely to live in families of lower socio-economic status and greater material deprivation. Their households are predominated by more frequent parental conflicts. Children are more likely to be maltreated and neglected (51), and less likely to get married and employed in adulthood (52). The quality of parents’ marital relationship has been repeatedly identified as important factors to children’s psychological outcomes (53, 54). The primary consequence of divorce (and of the parental conflict) is the decline in the relationship between parent and child (55). Marital conflict has been proved to be associated with various child adjustment problems, including internalizing (disobedience, aggression) and externalizing problems (depression, anxiety, low self-esteem), and impairments in academic and social functioning (56). COPSMI are more likely to feel negatively about themselves and experience excessive guilt and social difficulties.

3.2 Intervention programs

Prevention is better than a cure. Early interventions are used to foster resilience, in order to reduce the potential burdens of SMI to individual, family and society (57, 58). Intervention programs designed to meet these children’s needs and improve their psychosocial outcomes have been established. Appropriate preventative interventions have been successfully established in developed countries such as the United Kingdom (59), the United States (60), and Australia (61). Numerous evidence has suggested these programs can improve psychosocial outcomes of these vulnerable children and enhance their quality of life (62).

Social support plays a key role in ameliorating adverse outcomes for these children (63). Peer support group utilizes a peer setting wherein children can observe, listen to, and interact with peers in similar circumstances to promote personal health and growth. Instilling a sense of
belonging, peer support group can address children’s needs and issues collectively in a cost-effective manner (64). Children and Mentally ill ParentS (CHAMPS), an Australian peer support group intervention program which was first developed in 1995, targets children aged 8-12 years old living with parents suffering from SMI (61). It provides information about mental illness in an age-appropriate way. Through strengths-based approach, peer support programs aim at reducing isolation and improving social connectedness, building on children’s strengths and promoting resilience.

The other main type of intervention programs is family-intervention program, which focuses on minimizing family dysfunction and maximizing children’s support networks (65). The most prominent program, Family Talk, targets families with 8-15 years old children whose parents have been diagnosed as major depressive disorder or bipolar disorder (60). Family Talk employs a cognitive psychoeducational approach that consists of 6 to 10 sessions, with some directed to parents, some to children, and some to the whole family. They intend to reduce risk factors and enhance protective factors by increasing positive interactions between parents and children, and by increasing understanding of mental illness for everyone in the family (60).

3.3 Challenges

While significant improvements and achievements have been brought in past decades, two main weaknesses have been left over in this field. Firstly, beyond epidemiological studies and descriptive studies based on discourse of risk and resilience, there has been little research on how children’s actual daily lives are affected by their parental mental illness (66). Though COPSMI are primarily viewed as being ‘at risk’, little is known about how these children engage with their parents, peers, teachers, and healthcare professionals. Due to lack of research, what has not been acquired is the deep insight from the perspective of children. Qualitative research
(QR) is well suited to enhance our understanding of how children cope with various life situations (67). However, QRs often have small sample sizes that limit their application and generalizability. In addition, QR has been used to explore how health services and policies meet patients’ subjective needs in general psychiatry (68), while the subjective experiences of COPSMI have received little attention (69).

Secondly, little is known about this vulnerable population in developing countries. Since the setting of the Millennium Development Goals in 2000, substantial progress has been made in reducing child mortality rates worldwide (70). There is increasing research in child health in developing countries (71). Some areas have received much of attention and led to the implementation of effective interventions that can reduce disease related burden. While in other areas, such as mental health, comprehensive research approaches and the system application of research findings were still lacking. Gaps in resources for child mental health in LMICs have been summarized as: universal barriers to access, lack of program development and comprehensive policies, lack of data gathering capacity for country-level epidemiology and services outcomes, and lack of social services and continuum of care (72).

Indeed, there are very few evaluated child mental health intervention programs in LMICs, where the bulk of the limited resources are allocated to the provision of direct clinical services (73). Highest priority should be given to increasing resources in order to develop and implement of preventive child mental health interventions. Though adapting existed and effective interventions from developed countries could be the simplest way, there is no reason to doubt such programs could also be effective in LMICs in the absence of direct evidence from LMICs. China, a special developing country, should aim for a more rapid pace of the reform for child mental health.
4. Mental Health in China: History, actuality, challenges, and opportunities

4.1 History of Health Care System

China, officially the People’s Republic of China, is a unitary sovereign state in East Asia. With a population of over 1.4 billion (74), China is the world’s most populous country which is governed by the Communist Party of China. Covering approximately 9.6 million square kilometers, China is the world’s second largest state by land area (75). Since the introduction of economic reform in 1978, China has become one of the world’s fastest-growing major economies, and also the world’s largest exporter and second-largest importer of goods (76). Basic socioeconomic and demographic Indicators are shown in Table 1 (77, 78). China is a great regional power within Asia, and has been characterized as a potential superpower in the world (79).

Table 1. Basic socioeconomic and demographic indicators of China

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Year</th>
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<tr>
<td>UN development index ranking</td>
<td>90 out of 188</td>
<td>2014</td>
</tr>
<tr>
<td>Urban population (%)</td>
<td>57.3</td>
<td>2016</td>
</tr>
<tr>
<td>Poverty headcount ratio at $1.25 per day (PPP)(% of population)</td>
<td>1.9</td>
<td>2013</td>
</tr>
<tr>
<td>GINI index</td>
<td>46.5</td>
<td>2016</td>
</tr>
<tr>
<td>GDP growth annually (%)</td>
<td>6.7</td>
<td>2016</td>
</tr>
<tr>
<td>Gross national income per capita (current $)</td>
<td>8260</td>
<td>2016</td>
</tr>
<tr>
<td>Literacy(all, M, F)</td>
<td>96.4, 98.2, 94.5</td>
<td>2015</td>
</tr>
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However, when ‘New China’ was just established in 1949, over 80% Chinese people were living in rural areas and in absolute poverty. It’s hard to believe that this new country can deliver sufficient health care for all her population. After half a century, significant changes have taken place in China. Life expectancy has increased from younger than 40 in 1949 to over 70 in 2015 [latest health and epidemiological indicators are shown in Table 2] (80). Undoubtedly,
Chinese government has created a comprehensive, and to some extent, a successful health care system.

Table 2. Health and epidemiologic indicators of China

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Year</th>
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<tbody>
<tr>
<td>Average life expectancy at birth (total, F, M)</td>
<td>2015</td>
</tr>
<tr>
<td>Maternal mortality ratio (per 100,000 live births)</td>
<td>2015</td>
</tr>
<tr>
<td>Under-5 mortality rate (per 100,000 live births)</td>
<td>2016</td>
</tr>
<tr>
<td>Vaccination rates (% of DTP3 coverage)</td>
<td>2016</td>
</tr>
<tr>
<td>Death due to HIV/AIDS (per 100,000 live births)</td>
<td>2015</td>
</tr>
<tr>
<td>Death due to TB in HIV-negative people</td>
<td>2015</td>
</tr>
<tr>
<td>Median age</td>
<td>2015</td>
</tr>
</tbody>
</table>

Important lessons can be learned from the whole transformation of Chinese health system. The whole transformation of Chinese health system can be divided into four phases (81). In the first phase (1949-1983), health services were nearly free since government owned all health care facilities and employed all health care workforce. Great success has been achieved by using community health workers (Barefoot doctors) to provide basic health services at the village level. In the second phase (1984-2002), with the introduction of market economy, Chinese government reduced its role in health care sectors by dramatically dropping funding for health care facilities. Meanwhile, the government did not provide insurance coverage, and no private insurance company existed at that time. Without enough financial support, health facilities acted as for-profit entities in an unregulated market. This market-based health care pattern resulted in public anger and distrust towards health care institutions and staffs (82).

In the third (2003-2007) and fourth phase (2008 until now), Chinese government has undertaken a series of strategies to correct their mistakes. A health insurance scheme covering some hospital expenses for rural residents was introduced in 2003. Though it has been proved
insufficient to ameliorate health care problems in rural areas (83), it provided implications for subsequent reforms. After abandoning the market-based health care experiment in 2008, Chinese government turned to focus on providing affordable basic health care for all people again. Several considerate achievements have been reached since then. However, the general medical environment is still not optimistic in China. A huge gap for government expenditures exists between the western world and China (indicators shown in Table 3) (80). Total health spending accounted for 5.4% of GDP in China in 2012, well below the average of Organization for Economic Co-operation and development (OECD) countries (9.3%) (84).

While China has registered astonishing economic progress in past few decades, an insufficient health care delivery system should not also be ignored. Expanding medical supply chains in the developing world should draw lessons from many famous companies’ global-scale production and distribution models. Although there is much to be borrowed, there is even more which cannot be replicated. Lessons from the development of China’s health care system have shown that market principles can play an important role in health care delivery and regulate it in a right direction, but it should be the only guiding ideology. Experiences of China proved that completely profit-oriented health care model could create risks and destroy the whole system. The primary goal of any health system should always be providing affordable and accessible health care for all.

Table 3. Health system indicators of China

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Year</th>
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<tbody>
<tr>
<td>Government expenditure on health as a % of total</td>
<td>5.6 2014</td>
</tr>
<tr>
<td>Government expenditure on health per capita</td>
<td>731 2014</td>
</tr>
<tr>
<td>Population using improved sanitation facilities (%)</td>
<td>76.5 (63.7 in rural) 2015</td>
</tr>
<tr>
<td>Physicians density (per 1000 population)</td>
<td>1.49 2011</td>
</tr>
<tr>
<td>Nursing and midwifery density (per 1000 population)</td>
<td>1.66 2011</td>
</tr>
<tr>
<td>Number of hospitals</td>
<td>25860 2014</td>
</tr>
</tbody>
</table>
4.2 Mental Health History in China

The first psychiatric hospital for the homeless mentally-ill patients in China, which was funded by an American missionary John Kerr, was established in 1898 in Guangzhou (85). During the next 50 years, mental health facilitators were built very slowly in a limited number of large cities. After the founding of the P.R. China in 1949, mental health system was generally established. Psychiatric hospitals, with primary goals to maintain social security and stability, were gradually built in every province. Mental health professionals were trained in these facilities for the prevention and treatment of SMI. Home-based treatment and untrained “barefoot” indigenized care for SMI patients were promoted to replace westernized individual treatment (86).

Community mental health work started in Beijing, Shanghai, Hunan, Sichuan and Jiangsu provinces in 1958 following the first National Mental Health Meeting, where professionals were trained to develop work plans for the prevention and treatment of mental illness (87). During the Cultural Revolution (1966-1976), community mental health system almost ceased, and the admission, diagnosis, treatment in mental hospitals were governed by political ideologies and the Revolutionary Committees (88). With the economic reform began in 1980s, hospital-based service which was encouraged to make a profit has been the primary provision of mental health care. The number of financially dependent mental health rehabilitation centers has decreased during 1980s and 1990s (89).

After reconsidering principles and approaches for mental health care delivery, first National Mental Health Plan (2002-2010) was signed by the Ministry of Health, Public Security and Civil Affairs, and China Disabled Persons’ Federation in 2002 (90). It identified a series of targets which included establishing a mental health system led by the government with the
cooperation of different sectors, and raising the awareness of mental health among Chinese population.

4.3 The National Mental Health Service Reform

China accounted for 17% of the global mental and neurological disease burden (91). WHO estimated that mental illness would increase to account for 17.4% of all illness in China by 2020 due to increasing economic and societal stress (92). 100 million Chinese were suffering from mental health problems, while more than 16 million citizens afflicted with SMI, according to statistics released by China’s National Center for Mental Health in 2009 (93). The prevalence of any mental disorder is about 17.5%, and the prevalence of SMI is about 1.0%, based on an epidemiological survey published in Lancet in 2009 (94).

China is facing challenges in improving mental health services nationwide because of inadequate human resources for delivery of essential mental health service. The vast majority of Chinese mental health professionals are psychiatrists and psychiatric nurses who are licensed by Chinese Ministry of Health. In 2004, Chinese mental health human resources were quite insufficient (1.24 psychiatrists and 1.91 psychiatric nurses per 100,000 population), which was below the average mental health workforce worldwide (4.15 psychiatrists and 12.97 psychiatric nurses per 100,000 population) (95, 96). The numbers of psychologists and social workers were much smaller. Since there is a huge disparity among geographic regions, even such limited resources were mostly located in urban areas.

Though China has maintained a stable economic growth rate, the distribution of wealth was unequal. The average per capita income was CNY 23,821 in 2016, with an increase of 62.6% from 2010 nationwide. Urban residents had an average per capita income of CNY 33,616,
which was 2.72 times higher than that of residents in rural areas (97). China Family Panel Study found that the poorest 25% of households owned just 1% of the country’s aggregate wealth, while the richest 1% owned a third of the wealth (98). The GINI coefficient reported by this study was 0.73, which was much higher than official data.

It’s apparent that the wealth gap is increasingly growing. Wealth distribution has consequences for the access to mental health services. Rich people, who can afford medical expenses, can choose to go to a tertiary psychiatric hospital and seek help from psychiatric professionals directly without constraints, even when they are not actually ‘mentally-ill’. While people with great socio-economic disadvantages, who can get full remission just by some cheap antipsychotics, are often physically restrained and never get access to mental health care (99).

While Chinese mental health professionals had attempted different approaches to cope with these obstacles, it was difficult for them to identify a suitable and practical mental health model for China. With the long-term goal of rebuilding nationwide community mental health service, Chinese professionals decided to focus on a less ambitious target first. Government engagement is considered as a crucial segment for any nationwide health activities and reforms, especially for a one-party state like China. Social harmony and stability has always been considered as the priority for Chinese government due to its vast and multi-ethnic population. Therefore, focusing on patients with SMI, who have potential violent and social disruptive behaviors, was considered as a first and critical step (96).

In 2004, following the severe acute respiratory syndrome (SARS) outbreak, Chinese government decided to make an effort to rebuild the public health system (99). With guidance from WHO and international working groups, an integrated hospital and community treatment model for SMI named the National Continuing Management and Intervention Program (also
known as mental health reform program, and the 686 Program after its initial funding of CNY 6.86 million) was integrated into the national public health system by Chinese government. This event became a major historical milestone for mental health service reform in China (96).

The 686 Program, which is a patient-centered, function-oriented, and community-based model, aims at scaling-up nationwide basic mental health services and promoting human rights for people with SMI. The program prioritizes equal access to a basic package of community mental health services for SMI patients, especially for those with socio-economic disadvantages (99). The 686 Program focuses on promoting rehabilitation and recovery, family education and support, and making medications continuously available. Main activities conducted under the program included the identification, registration, evaluation, provision free treatment, and follow-up of patients with SMI (100).

Significant progress has achieved since the 686 Program was implemented. By 2005, 60 demonstration sites had been established, with two (one in rural area and one in urban area) in each province. By the end of 2012, demonstration sites had been established in 1578 districts. By 2009, 96.88 million general Chinese population (from 112 cities) were covered by this program, a total of 162 thousand patients were registered in this program and 42 thousand patients have received free medication and regular follow-up (96). By the end of 2016, 5.4 million patients had been registered in the program, which covered over 80% of all patients with SMI living in China. 88.7% of patients with SMI are under the management of health authorities, and receive mental health services and living subsidies (101).

In last decade, mental health service has been scaled up throughout China, which was also led by the 686 Program. By the end of 2015, the number of psychiatric institutions, where mental health service are primarily offered, reached to nearly 3000, compared with 1650 in 2010.
The number of certified psychiatrists exceeded 27,700, and the number of psychotherapists exceeded 5000 in 2016. In metropolis areas like Beijing and Shanghai, SMI patients are receiving more support services, such as free medication and more reimbursement for medical bills. The reimbursement limit of medication has increased to $110 per person per year, and the reimbursement limit for inpatient treatment has increased to $330 per hospitalization (102). Furthermore, families with SMI patients are eligible for a CNY 2400 annual subsidy from the municipal government in Beijing (103). Most recent mental health indicators in China were shown in Table 4 (101, 104).

### Table 4. Mental health indicators of China

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Hospitals, rate per 100,000 population</td>
<td>728, 0.05</td>
</tr>
<tr>
<td>Beds in mental hospitals, rate per 100,000 population</td>
<td>2352,00, 16.8</td>
</tr>
<tr>
<td>Psychiatric beds in general hospitals, rate per 100,000 population</td>
<td>13526, 1</td>
</tr>
<tr>
<td>Persons treated in mental health outpatient facilities</td>
<td>1527.18</td>
</tr>
<tr>
<td>Admissions to mental hospitals, per 100,000 population</td>
<td>85.9</td>
</tr>
<tr>
<td>Health professional working in the mental health sector</td>
<td>1.7 psychiatrists</td>
</tr>
<tr>
<td></td>
<td>4.1 nurses</td>
</tr>
<tr>
<td></td>
<td>0.4 psychotherapist</td>
</tr>
</tbody>
</table>

The 686 Program has profound implications for mental health services not only in China, but also in other countries with limited resources (105). The program has developed a new service model, which has linked tertiary hospitals to community health centers, and provided outreach services for all citizens in the community. It built a ‘rich database of experiences in community-based health reform’ (100), and provided an opportunity for mental health professionals to develop capacities of providing community-based care in reality. It has changed the original focus of mental health work, which was narrowly focusing on psychotic symptoms, and moved rehabilitation and recovery to the central of clinical activities.
4.4 Challenges and Opportunities

Despite all considerable achievements led by the 686 Program, enormous challenges for mental health service still exist in contemporary China. Firstly, even with health insurance and subsidies from the 686 Program, patients who are living under the official poverty line can still not afford the high medical costs. The 686 Program does not have enough funds to provide free treatment to all such patients. Secondly, fewer and fewer medical graduates are willing to work in psychiatric hospitals, which exacerbates the continuum of well-trained mental health professionals (96).

In 2016 National Health and Wellness Conference, Chairman Xi Jinping mentioned that mental health professionals need to work on the integrated management of mental disorder, especially strengthening the registration and treatment of SMI (106). Guidance on strengthening mental health services, which was issued by National Health and Family Planning Commission and other 22 departments in the end of 2016, firstly put forward specific policies and measurements for strengthening mental health service systematically (107). The World Health Organization defined the theme for 2017 World Health Day as “Let’s talk about depression”. Chinese National Health and Family Planning Commission also organized a series of advocacy campaigns promoting public awareness of mental health, around the theme “Facing depression jointly, Promoting mental health together” (108).

On the National Health and Family Planning Commission press conference, deputy director Bin Wang presented the progress of national mental health work (101). She especially mentioned that the management and treatment of patients with severe mental illness and their family members were still the key point of next period. “One-stop service”, which is in fact the integration of all supporting policies from Ministry of Human Resources and Social Security,
National Health and Family Planning Commission, and Ministry of Civil Affairs, should be advocated and popularized to improve the quality of mental health service.

With the release of the National Mental Health Work Plan (2015-2020) (109), China committed make improved mental health service a priority and uphold WHO’s Comprehensive Mental Health Action Plan (2013-2020) (110). With substantial support and investment from Chinese government, the 686 Program is without any doubt an excellent step in mental health revolution in China. In the midst of these achievements and also challenges, it is a good time to seriously consider adding new goals of the integrated mental health delivery.
5. Conclusion

Family is the fundamental unit in Chinese society. Basic family functions are to satisfy needs of its members. In Chinese culture, family presents some distinguishing characteristics with regard to its structure along history which were greatly influenced by Confucianism(111). According to Confusion teachings, social harmony is contingent on intra-family harmony. Intra-familial harmony is maintained when family members are respectful of each other and everyone is able to carry out his/her roles and duties (112). Therefore, SMI patients are seen as a direct threat to familial and social harmony which were fundamental to Chinese Confucian teachings (113).

Ramsay’s study analyzed narratives of Chinese caregivers for their family members with SMI (114). While studies of the Western countries featured the dramatic changes that SMI brought to afflicted individuals and their families, Chinese narratives were marked by a particular focus on the familial reactions rather than the impact on the mentally-ill individual per se. While Westerners expressed the tragedy of SMI in emotional terms, Chinese took on a greater material and physical dimensions, which required enduring efforts to rebuild and reconstruct broken lives and futures. The responsibility of caring for patients with SMI was placed on their family members by society and state. They must ensure their mentally-ill family member was well cared for and supervised. Decisions made by family members must take into account both familial concerns and social consequences.

The impact of the illness on family is significant. Family members’ experiences take great import in improving public health service support that is often limited and inaccessible, especially in LMICs. In recent decades, researchers started to pay attention to the illness experiences of individuals and how they construct and conceptualize their illness, after
reconsidering the narrow concern of biomedical explanatory model which was the contemporary dominance advanced by medical professionals (114). By far, research in this area focused most on patients’ experiences, with most work conducted in Western settings. Less attention has been devoted to the accounts of those who are living with these patients, especially in Asian settings such as China.

Guan and colleagues’ study reported changes in family burden among patients receiving treatment in the 686 Program (99). Family members reported significant improvements in caregivers’ experience with a reduction in rating scores on each of the measures of family burden (stigma, psychological pressures, economic burden, personal energy, and interpersonal relationships) in 2009 assessment. Although measures of stigma increased slightly from 2009 to 2012, the improvement in different categories of family burden ratings was sustained.

A large proportion of patients receiving regular treatment in the 686 Program have married. A significant number of new children who are at great risk of developing their own mental problems have arisen, which can be considered as an unintended social consequence of the 686 Program. What are the difficulties of these children and what are appropriate interventions for them? While Chinese government needs to substantially increase support to maintain and enlarge the 686 program, this is a critical time for us Chinese mental health professionals to propose new approaches of mental health delivery towards families affected by SMI, including patients and their dependent children.

To our knowledge, this is the first study focusing on children whose parents are suffering from severe mental illness (COPSmi) in China. Understanding the problem should lay a foundation for further improvement in health and quality of life for such children in developing countries. This study addressed the gap in developing appropriate intervention programs for
COPSMI through conducting a pilot study to explore the psychosocial impact of parental mental illness on their children’s health. We conducted qualitative interviews with SMI parents, affected children, and primary caregivers to understand their perspectives. We also expect this study provides foundation data for further intervention programs for COPSMI in China and other resource-limited settings.
Part 2

1. Introduction

This study employed a mixed-methods approach to explore the psychosocial impact of parental mental illness on children, and to understand experiences among children of parents with severe mental illness (COPSMI) in China. The views of children, parents with severe mental illness (SMI), and primary caregivers were sought to provide deeper insight into the parent-child relationship, and difficulties and needs of families and children.

COPSMI are a substantial and marginalized population. International research suggests that around 10% of children are exposed to parental psychiatric disorder (34-37). What is known about this population is based on research about their relatively high risk of developing SMI and a wide range of mental disorders (41, 42). In addition, they are also found to be at risk for a number of cognitive, social, and developmental problems (115, 116). The effects of social adversities accompanying parents’ SMI seem to be more detrimental to these children. Family context and social circumstances are important contributory factors for adverse psychological outcomes in COPSMI (44, 47, 48). More recently, research has started to focus on the subjective experiences and needs of these children, and accumulated some information about such children (67, 117).

Intervention programs designed to meet these children’s needs and improve their psychosocial outcomes have been established in developed countries (6, 7, 59-61), which have been shown to improve psychosocial outcomes of these children and enhance their quality of life (62). Though significant information has been accumulated, pervasive knowledge gaps remain in this field, especially in resource-limited settings.
China started to provide community-based mental health services for SMI patients in the past decade. In 2004, an integrated hospital and community treatment model for SMI (also known as the 686 Program for its initial funding of CNY 6.86 million) was integrated into the Chinese national public health system, which aims to scale up nationwide basic mental health services and promote human rights for people with SMI (99). Implementation of the 686 Program has resulted in significant progress. By the end of 2016, 5.4 million SMI patients had been registered and received community-based mental health services in the program, which accounts for more than an estimated 80% of all SMI patients living in China (101). Meanwhile, mental health services have been improved throughout China. The number of psychiatric institutions has reached nearly 3000, and the number of certified psychiatrists exceeded 27,700 in 2015 (103). Moreover, the Chinese government started to provide free antipsychotic medications and living subsidies to SMI patients and affected families in some areas (102, 103, 118).

Deinstitutionalization and community-based rehabilitation have increased the likelihood that parents with SMI can raise children on their own (32). According to the 2016 annual report, 53% SMI patients registered in 686 program are married. Though exact information about the fertility rates among SMI patients is lacking, the number of COPS MI in China is estimated to be over 1 million according to international data (34-37). Though the Chinese government started to provide support services for families affected by SMI, little attention has been paid to COPS MI. To the best of our knowledge, this is the first study focusing on subjective experiences of COPS MI in China. This study addresses a gap in information needed for developing appropriate interventions for COPS MI in China, which should begin by conducting a pilot study to explore the psychosocial impact of parental mental illness on their children. Quantitative assessments
and qualitative interviews were conducted with SMI parents, affected children, and their primary caregivers, to understand their experiences and needs.
2. Methods

This was a mixed-methods study conducted in Beijing, China. By combining quantitative and qualitative data, we aimed to cross-validate the findings and reach a greater understanding of the effects of parental mental illness on children. A cross-sectional survey was conducted concurrently with qualitative in-depth interviews. The qualitative data, which were obtained from different perspectives, provided a broader interpretation of the findings. The quantitative and qualitative data were separately analyzed and thereafter integrated during the interpretation of the results.

2.1 Participants

Recruitment took place between July 2017 and December 2017. SMI patients who were hospitalized in Peking University Institute of Mental Health, and patients registered in the 686 Program living in Beijing were considered as potential participants. Eligible SMI patients were contacted after they were identified as appropriate for inclusion in the study. After the patient and the primary caregiver agreed to participate, they were consented and at least one parent provided permission for their child’s participant.

Inclusion criteria for participants were: 1) Families include at least one parent in treatment for at least six months for any kind of SMI (including schizophrenia, bipolar disorder, schizoaffective disorder, and delusional disorder, according to ICD-10), and at least one child aged 8 to 17 years old; 2) Children should not meet threshold diagnoses for the above SMI; and 3) Families must have an adult who does not have any mental illness or considerable physical co-morbidities as the primary caregiver for the patient and the child. Patients who were acutely ill or actively suicidal, and families who were undergoing family psychotherapy were excluded.
2.2 Data Collection

Quantitative data were collected using questionnaires including a questionnaire developed for this study concerning basic demographic characteristics and caregiving activities, and the Strength and Difficulty Questionnaire (SDQ). SDQ was initially developed by Goodman in 1997 to measure children’s strengths and difficulties (119, 120). The SDQ can be scored using five subscales, including emotional problems, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial problems. Each of the five subscales is scored 0-10. Total difficulty score is a fully dimensional measure, with each one-point increase in the total difficulty score corresponding to an increase in the risk of mental health disorder (121).

Qualitative data were collected by conducting semi-structure individual interviews with SMI parents, their children, and primary caregivers. These interviews addressed 1) opinions about parent-child relationship, 2) impacts of SMI on children’s daily life, and 3) children’s and family’s needs. The first author, who is a female Chinese psychiatrist with experiences of interviewing, carried out all individual interviews. Individual interviews took place in private locations based on participant choice. An interview guide based on themes from literature review and researcher experiences guided the interviews. The interviews were audio-recorded with permission, and lasted from 40 min to 90 minutes.

2.3 Data Analysis

Quantitative data were coded on spreadsheets and checked for accuracy by researchers. Descriptive statistics were generated with STATA (Statacorp, College Station, TX, US). Continuous variables were described using means with standard deviations or medians with
interquartile ranges. Categorical variables were described as frequencies and percentages. Differences between continuous variables were compared with student t-test.

Individual interviews were analyzed using a conventional thematic content analysis approach (122). Seven interview transcripts were open coded to derive a set of initial codes, which were used to construct a codebook. The codebook was piloted and revised. The finalized codebook was used to directly code the entire database by hand. The resultant coded data was examined for themes relevant to the research question. Using an iterative process, these initial thematic categories were revised and elaborated through multiple examination of the coded dataset. The final thematic categories resulting from this process are presented in the qualitative results section.

2.4 Ethical Statement

This study was funded by Dubai Center for Global Health Delivery, and Department of Global Health and Social Medicine, Harvard Medical School. Approval for this study was obtained from the Institutional Review Board of the Harvard Faculty of Medicine (IRB17-0594) and from the Ethics Committee of Peking University Institute of Mental Health (2017-7-18-1).
3. Results

590 patients were assessed for eligibility; 84 patients who met inclusion criteria were identified. The prevalence of SMI patients with dependent children age 8-17 varied between communities, from 1% to 10%. Among eligible families, 45 families refused to participate; 39 families were included in this study. Among the 39 participated families, 17 parents with SMI, 13 children, and 15 primary caregivers who completed individual interviews were included in the qualitative section.

3.1 Quantitative results

Among 39 participating COPSMI, 35 (90%) were single children [18 (46%) were boys and 17 (44%) were girls], and 4 (10%) were children with siblings (with one boy and one girl in the same family). The average age for children was 12.7±3.3. Most children were students in school. 4 (10%) children aged 17 were out of school and working, while 2 (5%) of the children (aged 16 and 17) had discontinued school but did not have a job.

Of the families in the study, 26 (67%) had a mother with SMI and 13 (33%) had a father with SMI. The average age among SMI parents was 42.5±6.3. Of these parents, 31 (80%) had a diagnosis of schizophrenia and 20% had a diagnosis of bipolar disorder. 18 (46%) of the SMI patients had onset of SMI before they became parents. The median illness duration was 10 (3, 17) years. Detailed demographic characteristics of SMI parents were listed in Table 1.

<table>
<thead>
<tr>
<th>Table 1. Demographic characteristics of parents with SMI (N=39)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Marital Status</strong></td>
</tr>
<tr>
<td>Married</td>
</tr>
<tr>
<td>Divorced</td>
</tr>
<tr>
<td>Widowed</td>
</tr>
</tbody>
</table>
Table 2 described the primary caregivers for the mentally-ill parents and the children. The median age among primary caregivers was 55 (44, 67). There were 6 (16%) families where SMI parents’ primary caregivers were different from their children’s. Over half of SMI parents were involved in caring for their children, and 7 (18%) SMI parents were their children’s primary caregivers. While 14 (36%) children were primarily taken care of by their grandparents, 9 (23%) children were solely taken care of by their grandparents.

Table 2. Primary caregivers for SMI parents and their children

<table>
<thead>
<tr>
<th>SMI parents’ primary caregiver (N=38)</th>
<th>n (%)</th>
<th>Their children’s primary caregiver (N=39)</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self</td>
<td>14(36)</td>
<td>Healthy parent</td>
<td>18(46)</td>
</tr>
<tr>
<td>Parents</td>
<td>12(32)</td>
<td>Grandparent</td>
<td>14(36)</td>
</tr>
<tr>
<td>Spouse</td>
<td>12(32)</td>
<td>SMI parent</td>
<td>7(18)</td>
</tr>
</tbody>
</table>

20 children and 14 of the children’s primary caregivers completed the SDQ (Table 3). Total difficulties rated by children themselves were $8.8 \pm 4.7$, and by caregivers were $8.2 \pm 4.7$. No statistically significant difference was found ($p=0.72$). Prosocial problems were reported
worst in self-rated SDQs, with 10% as abnormal and 20% as borderline. Peer problems were reported worst in caregiver-evaluated SDQs, with 29% as abnormal and 7% as borderline.

### Table 3. Children and caregivers rated SDQ sores

<table>
<thead>
<tr>
<th></th>
<th>Children-rated SDQ</th>
<th></th>
<th>Caregiver-rated SDQ</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Normal (%)</td>
<td>Borderline (%)</td>
<td>Abnormal (%)</td>
<td>Mean ±SD</td>
</tr>
<tr>
<td>Emotional problems</td>
<td>100</td>
<td>0</td>
<td>0</td>
<td>1.4±1.4</td>
</tr>
<tr>
<td>Conduct problems</td>
<td>90</td>
<td>5</td>
<td>5</td>
<td>1.7±1.6</td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>95</td>
<td>5</td>
<td>0</td>
<td>2.8±1.8</td>
</tr>
<tr>
<td>Peer problems</td>
<td>85</td>
<td>5</td>
<td>10</td>
<td>2.9±1.9</td>
</tr>
<tr>
<td>Prosocial problems</td>
<td>70</td>
<td>20</td>
<td>10</td>
<td>6.9±2.3</td>
</tr>
<tr>
<td>Total difficulties*</td>
<td>85</td>
<td>10</td>
<td>5</td>
<td>8.8±4.7</td>
</tr>
<tr>
<td></td>
<td>Normal (%)</td>
<td>Borderline (%)</td>
<td>Abnormal (%)</td>
<td>Mean ±SD</td>
</tr>
<tr>
<td>Emotional problems</td>
<td>92.9</td>
<td>0</td>
<td>7.1</td>
<td>1.5±1.1</td>
</tr>
<tr>
<td>Conduct problems</td>
<td>78.6</td>
<td>21.4</td>
<td>0</td>
<td>2.9±2.5</td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>84.6</td>
<td>0</td>
<td>15.4</td>
<td>2.8±1.8</td>
</tr>
<tr>
<td>Peer problems</td>
<td>64.3</td>
<td>7.1</td>
<td>28.6</td>
<td>2.2±1.9</td>
</tr>
<tr>
<td>Prosocial problems</td>
<td>84.6</td>
<td>0</td>
<td>15.4</td>
<td>7.2±3.0</td>
</tr>
<tr>
<td>Total difficulties*</td>
<td>92.9</td>
<td>7.1</td>
<td>0</td>
<td>8.2±4.7</td>
</tr>
</tbody>
</table>

*Total difficulties were calculated by the combination of the first four subscales.

#### 3.2 Qualitative results

##### a. The cost of SMI and children’s financial sacrifices

Most SMI parents were unable to work due to psychiatric symptoms and sedative treatments, and had no principal source of income. The cost of treatment and medical expenses associated with parental SMI negatively impacted household income. In addition, at least one family member was required to care for the SMI parent, and therefore could not work outside of the home, further limiting their household income. In the face of this financial hardship, families had to make difficult choices among competing demands. Families in our study reported that key financial considerations included high mortgage costs and rent, as well as expensive tuition for in-school and after-school classes for children.

Children were aware of their families’ financial hardships, and reported trying their best to balance their family’ needs with their own. Children reported that they would not ask for snacks, clothes, or pocket money. They elected not to study in prestigious schools, but instead chose to enroll in schools that were less competitive but more affordable. Children chose to sacrifice themselves in order to reduce the family’s financial stress. A 16 year old boy whose
mother had schizophrenia described his condition: “I cannot continue school because we cannot afford it. I hope I can find a job and make a lot of money as soon as possible, so my dad does not need to work.”

b. “Missing” parents and self-supported children

Participants described the mental illness as a barrier to patient’s active parenting. SMI parents explained that their psychiatric symptoms prevented them from caring for their children; the same was reported by caregivers. The side effects of psychiatric medications, such as fatigue and sedation, also negatively impacted parenting capabilities. In addition to actual impairment, many SMI parents explained that they had lost confidence in themselves since the onset of their disease. They worried about not being able to properly take care of their children, and expressed concerns about not being “good enough” parents, which caused many of them to withdraw from their parenting roles.

Children reported that their mentally-ill parents were not always physically or psychologically available to them. They explained that their parents could not accompany them during key childhood activities such as studying and playing. Children expressed their needs for “psychological counseling” and “routine daily care,” which were not fulfilled by their parents. Children also described that their outlets for expressing distress were destroyed by their parent’s SMI. Children had to find an alternative source of support, or “make do without.” Some children indicated that they received support from other relatives, and some said that school became a refuge for them. Those who failed to find new outlets felt that they could only rely on themselves. As a 14 year old girl whose mother had schizophrenia described: “My mom is
mentally-ill; she cannot always understand my problems. I cannot rely on her, I only rely on myself.”

c. Fragile families and cautious children

For some families, the diagnosis of SMI precipitated marriage. SMI limited patients’ “abilities to fall in love”; thus many SMI patients had to marry strangers arranged by their parents. However, arranged marriages did not ensure a peaceful environment for families in this study. Participants reported that domestic violence towards patients was very common in such families, and explained that such domestic violence negatively affected their family relationships at all levels. In many cases the well parent disengaged from the marriage, and many reported not being willing to be involved in parenting activities.

For families for whom the SMI came after marriage, conflicts always came along with it. While SMI patients always quarreled with their partners due to SMI related problems, divorce was their solution when they failed to adapt their relationships. However, divorce was not the end of their family problems. There were still innumerable links between divorced parents and grandparents from both sides. Participants described that even after divorce, children still struggled with strained relationships among in-laws and an overall chaotic family environment. As a 15 year old girl whose mother had schizophrenia described her family: “If you ask me to use one word to describe my family, it must be ‘chaotic’. My parents quarrel every day. My mom also quarrels with my grandma. Everyone in my family seems to become more and more difficult. I am frightened but do not know how to help.”

Living in such fragile families, children expressed that they worried about their families, their mentally-ill parents, and also their well parents. Children reported feeling stuck in the middle of their parents who were hostile towards each other, and did not know how to balance
these tensions. They worried about their relationships with all family members. Participants also described that children had witnessed violent behaviors carried out by their SMI parents and directed towards other family members, which caused children to be upset or frightened. Participants reported that sometimes children were the ones who not only witnessed, but also had to react to these incidents. A 66 year old grandmother told about her own experiences: “One day she [SMI patient] suddenly grabbed my hair and hit my head. My grandson asked for help from the neighborhood. But it was midnight. He knocked on the neighbors, no one came to help.”

d. Children’s experiences of parental psychiatric symptoms

Participants told how the children’s daily life were invaded by their parent’s psychiatric symptoms. Positive symptoms (hallucinations and paranoia) were described as a source of embarrassment for children, and remained one of their primary concerns. SMI parents reported that their persecution delusions disturbed their children’s daily life and made them scared. Even worse, some patients reported that they would occasionally have delusions directly towards their children, and sometimes they could unintentionally harm their children.

Children described that they could not predict when their parents would be all right and when they would “get mad.” Children did not know how to deal with their parents’ symptoms, so they explained that they generally stayed away from their ill parents as a way to protect themselves. Some children also talked about witnessing their parents’ hospitalizations, which made them even more frightened and sad. As a 15 year old girl whose mother had schizophrenia described: “I came to the psychiatric hospital to see my mom. Since she refused to take medications, she was secured with her hands and feet tied to the bed. She could not resist.”
e. Stressed families and helpless children

Lacking a proper outlet for resolving SMI-related problems, SMI parents reported high rates of stress, which they passed on to other adult family members. Other adults absorbed this stress, but similarly lacked an outlet for their own stress. Our qualitative data revealed a chain of stress, with high levels of stress originating with adults and ultimately being passed on to children. Children reported having many negative emotions due to their parent’s illnesses. The most common emotional problems included anxiety, low self-esteem, and helpless.

One of the top concerns among children was worrying about developing mental illness themselves. They knew enough about SMI to be concerned that they could inherit the illness from their parents, but did not have enough knowledge to fully understand their parents’ SMI and their own risks. Children expressed feeling helpless and incapable of coping with the consequences of parental SMI due to lack of information. Unpredictability of parent’s symptoms also led to children’s negative feelings. Children were very cautious and worried when facing their SMI parents. Parents’ psychiatric episodes frequently recurred, even after family members had tried their best to prevent, which resulted in their felling hopeless about their future. As a 16 year old boy whose mother had schizophrenia described: “When God closes a door, he will open a window for you. Unfortunately, I cannot see my window.”

f. Disclosure of parental mental illness and isolation

SMI was considered as a grave crisis for these families. Patients and their adult family members reported feeling frightened by SMI and as wanting to avoid any potential effects of SMI on their children. Adults often hid parental SMI from their children. Though parents considered withholding information to be a protective measure, some children described feelings...
of being deceived. Children felt that they were isolated by their parents and not considered as fully members of their families.

SMI also affected children’s peer relationships in school context. Participants reported their children being bullied in school because of their parents’ mental illness. Children also tried to hide their parent’s mental illness from others because they did not want them “to see me differently”, and “to be sacred too.” In order to protect their parents and themselves, some children reported that they chose to stay away from their friends. A 14 year old girl whose mother had schizophrenia explained: “I am afraid my mom could be made to feel anxious by others. If someone comes to our home, she becomes suspicious and worried that he could steal something. So I cannot invite friends to my home.”
4. Discussion

This mixed-methods analysis of parental mental illness captures the experiences of participants and potential effects that parental SMI may have on their children’s well being. This study represents an important exploratory investigation of how SMI interrupts normal life experiences of young children affected. Our findings showed that the presence of a parent with SMI in the family resulted in considerable disturbances to children’s daily lives, with both obvious and subtle effects on children. The triangulation of data from multiple informants, combined with integrated quantitative and qualitative data strengthens and validates these findings.

Both quantitative and qualitative results in this study demonstrated the financial impacts of parental SMI, which have been reported in almost all previous studies in this field (3, 5, 67, 123, 124). While quantitative results described the scope of financial difficulties in the family, qualitative results described the direct impacts of such difficulties on children. While previous retrospective studies explored the effects of parental mental illness on adult children (125, 126), we directly interviewed young children, thus providing access to children’s own descriptions of their experiences, and to mechanisms whereby children’s daily lives were affected. Our results yielded information of how children cope with financial hardships associated with parental mental illness. Lacking appropriate support, children in this study sacrificed themselves to support the overall wellbeing of their families. Specifically, children sought to minimize their own needs to reduce family stress.

Consistent with previous studies (5, 67, 127-129), our results also confirmed that SMI prevented parents from fulfilling their responsibilities. Although attachment problems were not specifically assessed quantitatively, our qualitative results suggested that COPSMI experienced
difficulties in establishing close relationships with their parents. Multiple factors that could negatively impact a child’s attachment with their parents were identified, including inadequate provision of daily care, overall neglect, and being estranged from parents. While previous research documented the association between parental mental illness and insecure attachment (130-132), our study offered insights into why COPS MI experience challenges in establishing secure attachments. Specifically, our data demonstrated that psychiatric symptoms directly interfere with many parents’ parenting capacities. Furthermore, SMI parents withdrew from their parenting roles out of fear that they were not “good enough.”

In contrast to studies conducted in other settings (133-136), none of the children in this study were primary caregivers for their mentally-ill parents. This may be an artifact of the inclusion criteria for this study, where an adult had to be identified as the primary caregiver for the patient and child. Further investigation is needed to determine whether children in this setting are in fact acting as primary caregivers for their mentally-ill parents. Nonetheless, children in this study were not shielded from the stress caused by parental mental illness. Previous studies have documented the family burden brought about by SMI (5, 137, 138). Adult family members assumed the stressors associated with SMI, and transferred their stress to children through a specific “stress chain.” Young children, who were at the receiving end of this stress chain, became the recipients of all stresses experienced by different family members, and emerged as the most vulnerable members of the family.

Research data have demonstrated that COPS MI are likely to be exposed to parental conflicts and family separation (49-51). Though our quantitative results failed to find a higher divorce rate compared with the general divorce rate in the study setting (139), qualitative results confirmed high risks of COPS MI from this perspective. Even when SMI parents were able to
remain married, participants in this study reported that the well parents were not actively involved in parenting responsibilities. Furthermore, our data demonstrate that the presence of a parent with SMI in the family eroded the relationships between in-laws. In contemporary China, multigenerational co-residency is common, and most grandparents are involved in the responsibilities of caring for their grandchildren (140, 141). The erosion of relationships with the extended family emerges as another mechanism whereby young children are adversely affected by parental mental illness. While most research emphasizes the impact of parental conflicts on children, our results provide a clear image of the chaotic family environment in which Chinese COPSMI were living.

While the literature on COPSMI has acknowledged the intergenerational genetic inheritance of SMI (39, 42, 43), little research has attempted to examine children’s subjective experience in such transmission. Anxiety and helplessness were the most common emotional problems reported by COPSMI in this study. Fear of developing their parent’s mental illness was found to be a predominant cause of anxiety and worry. Studies in other settings revealed that hiding SMI from children was a common strategy employed by families to protect their children (142, 143), which was also employed by families in this study. However, our data demonstrated that shielding children from parental mental illness resulted in a breakdown of communication within the family, which exacerbated children’s fear and anxiety. With incomplete information and lack of support, children expressed feeling helpless in dealing with parental mental illness related problems.

Social isolation is an ongoing component in the everyday experience of people with SMI and their families (144-146). Consistent with previous studies (147), our data demonstrate that COPSMI had problems with their peers and felt isolated in their school environments. In
addition to being bullied due to their parents’ mental illness, COPSMI stayed away from their peers to avoid embarrassing consequences of their parents’ mental illness. Moreover, our results highlighted that some children isolated themselves from their peers to protect the well being of their SMI parents. Children made such social sacrifices to protect their families and themselves.
5. Limitations

This study has a number of limitations. Firstly, since this is the first study focusing on COPSMI in study setting, it was difficult to enroll a large number of participants. Lack of study power in the quantitative component is a major limitation of this study. Second, the effect of parental mental illness on children is considered as a sensitive topic among SMI patients and their family members. Some interviews (n=4) with child participants were conducted in the presence of their adult caregivers, which may have affected children’s response. Third, this was a modest exploratory pilot study with a small number of families in one city in China. While these results may be applicable to other regions in China, we recognize that themes presented in qualitative results may lack of generalizability to other study settings.
6. Conclusion

The findings of our study highlight the psychosocial impact of parental SMI on their children in China. Findings in this study suggest that while families are struggling with difficulties associated with SMI, COPSMI are facing specific risks and challenges that require additional support and protection. Due to numerous barriers they experience, COPSMI in China have a difficult time accessing mental health services. They remain largely invisible to health service providers. Identifying COPSMI and providing referral information to relevant support services is particularly important for these children. Mental health professionals who work with adult mentally-ill patients need a better understanding of all aspects of psychosocial impacts of parental mental health problems on children in order to target assessments and future interventions. The implications of findings from this study also suggest that the provision of family-focused care, including child-centered education, may be an effective approach to reducing risks related to parental mental illness. Our study demonstrates the acute vulnerability of COPSMI in China, and highlights that their specific social and psychological needs remain unaddressed. Further research with sophisticated designs is needed to develop appropriate interventions to reduce the vulnerability of these children, and institute appropriate policies and practices to meet their specific needs.
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