



# Understanding the Experience of Living With a Parent With Severe Mental Illness in China From Multiple Perspectives: A Qualitative Exploratory Study

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**UNDERSTANDING THE EXPERIENCE OF LIVING WITH A PARENT WITH  
SEVERE MENTAL ILLNESS IN CHINA FROM MULTIPLE PERSPECTIVES:  
A QUALITATIVE EXPLORATORY STUDY**

**MIAO XUE**

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Understanding the Experience of Living with Parental Severe Mental Illness in China from Multiple Perspectives: A Qualitative Exploratory Study

**Abstract**

Extensive negative effects of parental mental illness on family life and children's development have been widely studied across contexts and diagnosis of parental mental disorders. Several supportive interventions have proven to be effective and increasingly implemented in the service system in high-income countries. Little is known about this issue in resource-limited settings, such as China. This study aims to illuminate the experience of living with a parent with severe mental illness in China from multiple perspectives in a qualitative exploratory approach. It is hoped that findings will be used to inform further development or adaption of contextually appropriate and culturally sensitive target interventions in China. A series of in-depth individual interviews were conducted with four group of participants: children of parents with severe mental illness (COPSMI), parents living with severe mental illness (PSMI), other caregivers of the child in the family (OCGC), and service providers (SP). One overarching theme was identified from each group respectively: children live with complex and incomplete care, parenthood was like a roller coaster experience with primary care-giving roles often withheld from them, non-parental child caregivers took on a doubly challenging work, and most service providers are largely blind to the needs of children and the role of parenting in the patients they serve. In discussion, commonalities and uniqueness of experience living with parental severe mental illness in China were summarized to propose four recommendations: 1. Disclosure is inevitable and secrecy leads to significant negative consequences so that children are better to be informed with clear and appropriate information. 2. Empowering PSMIs to engage in parenting role could benefit both parents and children. 3. Clear systematic information and evidence-based guidance are needed to create shared understanding. 4. Needs of other family members should be also taken into consideration in the supportive service given the extent they engage in parenting role. 5. More data and evidence-based advocacy are needed to promote system change.

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## **Part 1: Political Economy/Background**

### **Introduction**

Xiao\* and I met the first time in a community activity for people with severe mental illness, in which I participated as a volunteer, in a hot summer in Beijing. (\*We have changed her name to conceal her identity.) That was the second year of my work in a psychiatric hospital, where I was mainly conducting psychological assessment and evaluation for people who were experiencing mental health struggles or episodes. People I met in the work usually came in at the worst moment of their lives filled with sadness, helplessness, anxiousness, frustration, anger, and hesitation. A significant part of that work involved managing conflicts and comforting emotional people.. Based on that work, I formed an image of people with mental illness based on seeing so many people in crisis. They were vulnerable and poor patients who were desperate for help. Being cured from mental illness seemed the only way to improve their lives. Helping them to be relieved of their symptoms was the most important mission as mental health professionals.

However, is that true? Is their mental health disorder the defining aspect about them and their lives? I didn't know. I didn't have an opportunity to ask myself these questions until I met Xiao in that community activity. Xiao attracted my attention immediately after she entered the room because she brought along a little girl, and she was the only person who showed up with a child that day. She introduced the girl to the group as her daughter. She apologized that she had to bring the little one with her because her husband was at work and no one else could help to take care of her during this time. That was the first moment I realized people with mental illness are not only people who need to be cared for, they also might be caregivers for others, in particular, they might be parents of children. Later, Xiao had to leave early because her daughter got bored and cried to go out. My encounter with Xiao was very short. Though I didn't get chance to talk

with Xiao in private, her warm smile to her daughter stayed with me. I did not reflect much more on my thoughts on this experience because I quickly became buried in my work.

Luckily, soon after that I joined a research team led by one of the psychiatrists in the hospital and took part in their project in my free time. They had just started a new project about transgenerational mental health as part of a bigger international group, who aimed to push preventative programs for children and adolescents whose parents have a diagnosis of mental illness. By joining this project team, I began my discovery of parental mental health. The fuzzy thoughts I started from the encounter with Xiao were finally articulated into a formal concept of parental mental illness. Unfortunately, lack of funding ended this project. However, the experience we had has helped to orient our own project. The discussion and interest in children whose parents live with severe mental illness existed long before the international project. The idea was developed by a couple of psychiatrists, who were the lead of the research team, after working in the 686 Project. The international project was an opportunity for them to articulate their discussion into a formal project and work on parental mental illness in China.

The 686 Project<sup>1</sup> was the biggest initiative launched in national mental health reform in China since 2004, and was also named “Central Government Support for the Local Management and Treatment of Severe Mental Illnesses Project”. It largely built up the community mental health system and services for people with severe mental illness in particular. This effort has significantly improved the treatment outcome and functioning recovery of people with severe mental illness, and has consequently resulted in dramatic progress of re-engaging people with mental illness with their family and in social life. Meantime, it meant an increased number of children and families living with parents who have a diagnosis of severe mental illness and the project increased participation of parents with severe mental illness in parenting roles of their children.

Because of the increased significance of the issue of parental mental illness, the research team launched an initiative, Care for Family 花园 (CAFF), in 2018 at the 14<sup>th</sup> annual meeting of Chinese psychiatrist association in Kunming. CAFF aimed to support the well-being of children and functioning of families living with parental mental illness. One of the funding members, Dr. Ma Hong, said that CAFF could be perceived as a grandchild of the 686 Project. CAFF is a continuous effort to tackle the unmet needs of people with mental illness and improve the quality of their lives.

CAFF started with a vigorous effort to raise awareness on the issue of parental mental illness among mental health professionals and gathered practitioners who were interested in the effort to build up a workforce network. A series of workshops and training programs were organized to learn about experience and evidence-based approaches in other countries, where targeted services were already implemented, to strengthen professional competence on dealing with the issue. Experts in the field were invited to share their lessons from the practice and support the exploration of contextually adequate and culturally sensitive service models for Chinese families.

Since 2018, CAFF has also launched efforts to raise awareness of parental mental illness to the public by sharing relevant information and stories in social media and enhancing the understanding of the issue through various activities. For example, CAFF organized national and local summer camps for families where a parent has a mental illness (FaPMI). It has now become apparent that effective evidence-based interventions to make sustained improvement and to provide systematic support are urgently needed.

The research project for this thesis was born out of this agenda to develop and adopt supportive interventions for children and families living with parental mental illness. The first step was to understand the issue of parental mental illness within the Chinese context: what happened in these families? What is their experience of living with parental mental illness? What are the commonalities and differences compared to other countries? What specific issues need to be addressed in these Chinese families? This research project, “A qualitative study on lived experience of Chinese families with parental mental illness” was designed and conducted to answer these questions. We will present that project and results in detail in Part Two of this paper.

During my time in the field, I was able to meet with Xiao again and hear her stories of being a parent living with bipolar disorder. (Xiao was not recruited as a participant in the study due to the recruitment procedures required by the Institutional Review Board.) She invited me to her home and we spent some time with her family. What I heard and observed of her experience as a parent living with mental illness was similar to what I learned about many other participants in the study. Being a parent is an important part of her life. Taking good care of her children is her highest priority.. Mental illness is a part of her life and probably will be something she deals with her entire life. However, her mental illness does not define who she is and will not take over the important parts of her life. Getting to know her and many others like her showed me that they are more than just patients with mental illness. Even more important, they are parents of their children. Mental health professionals must help parents living with mental illness engage with their role as a parent. Mental health professionals should also support the children so they can have their parents with them.

Mental health is a complex historical, cultural, societal and health issue. Parental mental illness brings in further complexity by its interaction with family and children. In order to capture

this complex picture of parental severe mental illness in China and to better understand its convoluted interrelationship, we will present contextual background in Part One of this paper. This background piece will uncover the socioeconomic and political context of the research with information about China over the past seven decades, from 1949 to today, and how it facilitates the change in the health/mental health system, stigma around mental illness, and family care. However, given the extremely rapid and complex transitions China experienced during this time, we will only highlight critical milestones to give an outline and trend of the changing process. Moreover, the author acknowledges the multi-directional and dynamic nature of these changes, and that one change could lead to positive, negative, and mixed consequences. All these changes are judged in a particular time and context of the history.

## **China from 1949 to today**

### **Population**

According to United Nations data<sup>2</sup>, in 2019, China has nearly 1.4 billion people, and is the most populous country in the world. The government has used population control as a political tool resulting in various social and health consequences<sup>3-5</sup>. From 1949 to 1979 the population doubled from 540 million to 969 million, closely following the change of the political landscape<sup>6</sup>. China experienced a century of wars from the late Qing dynasty including the Opium Wars, the Taiping Rebellion, Sino-Japanese war, Boxer Rebellion, and Xinhai Revolution, World War I, the Second Sino-Japanese War and the Civil War<sup>7,8</sup>. In 1949 the People's Republic of China (PRC) was established in a great urge for reconstruction, reformation and development, which required a substantial work force. Leaders, including Chairman Mao, perceived a large population as an asset. Mao wrote, "People are the most precious things of the world. Under the leadership of the communist party, as long as there are people, any miracle on earth can be created..."<sup>9,10</sup> simplified

as “More people, more power”<sup>11</sup>. Thereby the government encouraged reproduction in that period through various health and social policies<sup>12,13</sup>. For example, sterilization and abortion were more strictly restricted in healthcare and the import of contraceptives was prohibited. Not surprisingly, this series of actions caused a rapid growth in population<sup>14,15</sup>.

However, since the late 1970s, a trend of change in policy was led in response to the recognition of production and economy could not keep up with the growing population and was even damaged by it<sup>14</sup>. Subsequently, the government implemented an extensive birth control program called the One-Child policy nationwide to curtail the population growth<sup>14-18</sup>. The government largely mobilized the health resource to support this birth control campaign and family planning was promoted at the largest scale. This focus on family planning included improved health care, which significantly raised life expectancy<sup>19</sup>. In 2019, the average life expectancy of women and men in China was 87 and 81 respectively as compared to 42 and 39 in 1950<sup>20</sup>. This policy has had direct impacts on people’s mental health due to its implementation. The strict population policy during last 40 years has had broad effects on the nation’s development and social transitions, which produced significant unintended social consequences in people’s every day life<sup>3,21</sup>. For instance, one of the most outstanding aspects was the change on family structure and size, and subsequently the change in patterns of family care.

Today, China’s population has entered a new era. The aging population is a major threat to the future of the country<sup>22</sup>, specifically in the subject of our interest, family care<sup>23</sup>. One important legacy of the One-Child policy was the “4-2-1” phenomenon<sup>24,25</sup>, in which three generations coexist in a family with one child, two parents and four grandparents. Together, this has led to an unprecedented burden on the next generation, particularly in terms of family care. To counter this growing crisis, the Chinese government decided to abolish the One-Child policy and allow, and

even encourage, couples to have two children since October, 2015<sup>26</sup>. It is still too early to produce a comprehensive analysis on the impacts of the new Two-Child policy on people's lives given the short implementation of this policy. However, predictions based on the trends have made and concluded that it will have a positive impact on Chinese society.

## **Economy**

China has become one of the leading powers in the global economy. Over the last 70 years, China has experienced spectacular economic reforms, which lifted over 850 million people out of extreme poverty<sup>27,28</sup>. According to World Bank data<sup>29</sup>, only 0.5% of the total Chinese population still remained in extreme poverty by 2016, having fallen from 66.2% in 1990. However, when the PRC was built in 1949, the war years left extreme economic destruction<sup>30</sup>. From 1949 to 1979, planned economy predominated under the political emphasis of socialist development strategy, in which the state had control over almost all economic activities, such as production goals and pricing<sup>31,32</sup>. As a result, state-owned enterprise became the major and nearly the only actor playing in the market. From 1979 onward, the government started shifting gradually to a market economy model and opening up to the global economy to accelerate the economic growth and meeting the rising needs of the people<sup>33</sup>. A famous slogan of Deng Xiaoping<sup>34,35</sup>, a leader of China at that time, articulately captured the core idea of the reform "It doesn't matter whether the cat is black or white, so long as it catches mice." This means that the economy and productivity were prioritized over all development plans in the country. However, an unfortunate flip side was the increasing shame and stigma for the poor and disabled. Industrialization and urbanization largely reinforced the economic growth, and, reciprocally, were reinforced by this growth<sup>31-33</sup>. The emergence of self-employment and private business, trade liberalization, reform of state-owned enterprises, large labor migration from villages to cities, and marketisation of the healthcare system in particular,

were critical events led by the economic reform, which, evidently, had challenged the traditional norms and values of people on family and social life.

## **Rapidly changing society**

### **Health/Mental health system**

During almost all his governing years, Chairman Mao made unprecedented political decisions to implement China's national healthcare system<sup>39</sup>. For most of China's history, healthcare was provided by private practice and perceived as a personal responsibility. By the early 1950s, following the socialist ideology of public ownership and egalitarianism, the government built a health delivery system with a three-tiered structure consisting of country hospitals, commune healthcare centers and village clinics, all fully funded by the state<sup>39-41</sup>. At that time, well-known "barefoot doctors", who were farmer or folk healers and only received short and informal medical training, emerged in response to the extreme shortage of medical professionals and healthcare services<sup>42-44</sup>. They provided treatment for common diseases, delivered preventive health interventions, and produced simple drugs. The government put tremendous efforts into building health infrastructure and training medical personnel. As a result great progress was made on improving the health outcome of people, for instance, the maternal and child health systematically supported by the healthcare system led to a substantial reduction on maternal mortality rate<sup>45</sup>. However, under the impact of market-driven economy reform, a dramatic transformation was applied to the healthcare system with promotion of privatization and commercialization<sup>41</sup>. The public expenditure on the healthcare system was radically decreased as the focus shifted to profit-driven health services which initiated a series of changes<sup>42</sup>. Skewed

distribution of health resources in favor of urban healthcare institutions increased health disparities between rural and urban areas. With booming urbanization and labor migration, by 2004, nearly 80% of the government health spending was allocated to healthcare services in the cities<sup>48</sup>. The profit-driven model of healthcare service has significantly threatened the doctor-patient relationship and dropped the trust to medical professionals to a new low<sup>49,50</sup>. A significant trigger of the reorientation to public health was the pandemic caused by severe acute respiratory syndrome (SARS) in 2002<sup>51</sup>, initiated from Guangdong Province and soon spread out to the entire nation and many countries around the world. This outbreak was a hard jolt to the political leadership, economic growth, and social development, which flew a red flag on China's public health infrastructure<sup>52</sup>. To address the various issues of the overhaul and increasing challenges of accessibility, affordability, and equity in the healthcare system, the national health commission of the PRC launched a new round of healthcare reform<sup>53-56</sup>.

China's mental health service was reformed significantly under these efforts<sup>57</sup>. For the first time, mental health service was included in the public health system, which brought additional resources and government funding to tackle the difficulties in the service and reshape the service delivery model<sup>58,59</sup>. Before the reform, many financially dependent community-based mental health facilities and rehabilitation centers had to shut down or convert into smaller-scale psychiatric hospitals due to the marketization of mental health service, which led to increasing costs and burden of disease on families with mental health issues and contributed to larger disparities in access to mental health service between rural and urban areas, bigger treatment gap, and widespread stigma against mental illness. The reform included the 686 Program<sup>60,61</sup>, an innovative approach was to address disparities in access to mental health care, to increase community-based mental health infrastructures and to improve quality of care prioritizing

resource-limited areas and people living in poverty<sup>62</sup>. The 686 Program provided medical treatment and follow-up services and abolished the practice of restraining people with severe mental disorders in cages, ropes, chains and dehumanized living conditions<sup>63</sup>. The 686 Program is in an on-going effort to scale up to the entire country and address inequality as well as ensure humane treatment in mental health care. At the same time, the series of reforms has raised awareness among mental health professionals to recognize mental illnesses as more complex and socially rooted diseases, which need care and support beyond just targeting the symptoms of the disorder<sup>64</sup>.

Thus, this is an extremely critical moment to bring families into the picture of mental healthcare. Families are generally the main caregivers in Chinese culture. According to a report by Dr. Phillips, over 90% of Chinese people who have major mental illnesses live with their families<sup>65</sup>. The families are highly influential to the recovery of the patients. In recent years, family care has been formalized and introduced to the mental health system<sup>66</sup>. Generally, families are able to provide basic physical needs but unable to address psychological complications of the patients. Families often struggle substantially due to the lack of appropriate approaches to care. In addition, there is little recognition from the health professionals and policy makers to support the healthy members in the families, who are living in highly exposed environments and under great pressures.

### **Stigma on mental illness**

The burden of mental illness is not only caused by the stigma of the illness itself but also the social, political, economic and structural implications, which lead to inadequate access to healthcare, uneven distributed funding and resources and a fragmented hospital-centered delivery system<sup>67</sup>. Many people hold deeply-rooted beliefs that link mental illness to madness, absurdity,

foolishness, lunacy, and other types of negative images<sup>68</sup>. Stigma against people with mental illness is a world-wide phenomenon. As a result, individuals with mental illness are robbed of the opportunity to be treated equally and fairly by others.

Beginning from Erving Goffman's landmark work on stigma<sup>69</sup>, increasing explorations of stigma contributed to a profusion of literature in a wide range of disciplines, including sociology, psychology, anthropology, and medicine<sup>70,71</sup>. Studies have identified the experience of stigma has both material and mental consequences of social exclusion, disapproval, devaluation, and dehumanization on the lives of the stigmatized<sup>72</sup>. Being discriminated against affects the individuals with the mental illness. However the negative impact extends beyond the individual, impacting family members<sup>73,74</sup>. Moreover, mental health professionals also report experiencing stigma due to their work in psychiatry<sup>75</sup>. Arthur Kleinman addresses this issue in Chinese context "the stigma associated with mental illness is so powerful that it attaches not only to the seriously mentally ill but also to their families"<sup>76</sup>. In addition, an emphasis on "face" (面子, Mianzi) was raised to attach the threat of stigma in moral life in particular<sup>77</sup>. Face was perceived as a human capital, then losing face was a damage to the moral stand of the individuals with mental illness. Furthermore, Paul Farmer indicates that structural violence causes AIDS-related stigma<sup>78</sup>, so it is possible that structural violence also causes stigma around mental health issues. Additionally, Jinhua Guo writes in his book<sup>79</sup>, *STIGMA: An Ethnography of Mental Illness and HIV/AIDS in China*, "government often utilizes stigmatization as a necessary and effective measure of social control in the face of social crisis and public health crisis." After the field study, Guo proposed "structural violence is rather the embodiment than the root of stigma".

Following the revolution of psychiatric care and anti-institutionalization movement in the western mental health system<sup>80-82</sup>, China has developed and extended its hospital-centered services to a broader hospital-community integrated model<sup>83</sup>, through which mental illness treatment was largely moved from an isolated corner to a broader community level. This meant that individuals with mental health challenges had more contact with communities and experienced stigma more, and that their families also experienced stigma since the family member was no longer institutionalized, but instead in the community with the family<sup>84,85</sup>. However, de-stigmatization of mental illness was not progressively promoted in China in comparison of the development in other areas. The primary efforts on de-stigmatization by the professional community and mental health system were on the improvement of treatment and service access to people facing psychiatric challenges. The first national mental health law to regulate treatment was enacted in late 2012<sup>86</sup>, and was as a remarkable milestone of de-stigmatization progress. Yet the massive progress of de-stigmatization was mainly carried out by the increasing interest in psychology in the Chinese society and with the development of other social processes, particularly the technology revolution.

### **Family care**

The burden of care on family for psychiatric patients is not unique to Chinese culture<sup>87</sup>. However, the extent of the involvement of family members in care is significantly higher among Chinese families when compared with families from other countries. People living with mental illness, especially severe mental illness, rely heavily on care and support from their families as a result of the family caring tradition in China as well as reinforced by current healthcare policy to reduce the burden on the health care system. In contrast to many western countries, China is a collectivistic society and family-oriented culture<sup>88</sup>. Traditionally, value of family is always honored over the value of individuals<sup>89</sup>. Sometimes, this could mean great personal sacrifice, for

instance, arranged marriage was used as bond between two families. It was also common in China to have several generations of people all living together, and families had strong social bonds with one another. “Four generations living under the same roof” (四世同堂, Si Shi Tong Tang) was an ideal family model<sup>90</sup>. This idea has been weakened gradually over the past decades by the social economic and political transformation in China<sup>91</sup>. Younger generations do not follow the tradition; however, this ideology of family still deeply rooted in people’s minds informally. The family is still the basic building block of Chinese society and the family bears a large proportion of responsibility for care of its members.

Notably, industrialization, modernization, urbanization and globalization are essential components that contributed to the transition of traditional to modern family structure, size and values<sup>92,93</sup>. For example, a man living in Beijing thirty years ago usually started his day with a group breakfast with his family and sometimes neighbors in their yard. In this courtyard arrangement, usually six families shared one common space in the middle with separate living spaces for each family. Lives were very much integrated in that courtyard. The life in the courtyard was vividly described by an old Chinese proverb called “close neighbors are better than distant relatives.” After breakfast, people usually biked or walked to their workplace. Buses and other public transportation were not readily available as they are now. People usually took leftover food from home as lunch in an aluminum lunchbox. Most people worked from 8:30 am to 5:30 pm with a lunch break. For most worker households, which were called double-income families, could not take care of their child after school. Usually, children living close would go back home and play together in neighborhood (胡同, Hutong). Seniors living in the same Hutong often help to look after them and sometimes, prepared dinner for the children whose parents came back very late

from work. This structure greatly represents the collectivism culture of Chinese life. People were tied to both their families and the communities. However, things have changed now<sup>94</sup>. People have moved from yard life to high-rise apartments. People have very little connection with their neighbors. Life has narrowed to the family itself<sup>93</sup>. Plus, the rising value of individualism distances the connection among people<sup>95</sup>. This heavily increases the burden on caregivers because they cannot rely on their extended community for help. If people do not have families nearby or strong connections with their neighbors, it can be challenging for the healthy parent in a family to look after both a child and a partner with severe mental illness. However, it is much easier to hide the issue of mental health from neighbors since people have much less interest and engagement in others.

Urbanization and industrialization have changed life for families who moved into the city, and also have changed life for those families who stayed in the countryside. Many young people move to a bigger city to seek jobs and better opportunities. Migration left a lot of children, seniors and persons with disabilities are behind in the villages with an insufficient support system to assist in their lives.

The One-Child policy is another major factor in the that impacts how families handle mental illness. Traditionally, couples had more than one child. After the One-Child policy was established in 1979 , the family dynamic changed remarkably. The importance of that one child in the family became exaggerated causing parents to try their best to provide an ideal perfect environment to their children by preventing any potential disturbances. Therefore, it became extremely challenging to tell the children about their parent's mental illness. A study has shown that in Beijing, 56% of relatives of patients with schizophrenia kept the secret in the families<sup>96</sup>.

The intention to protect their children become the greatest barrier to disclosing parental mental illness.

The issues in industrialization, urbanization, modernization, migration wave and one-child policy have greatly contributed to the transition of family structure and family value, which affects how family handle the parental mental illness and support children in these families.

## **Conclusion**

In closing, families living with a parent with severe mental illness also have been living in this changing society and experiencing their everyday lives in the broader context of the socioeconomic and health transitions. By conducting the field study, we expect to get a more in-depth understanding of the issue of parental mental illness in China and how it has factored into the everyday life of members in the family. The project was designed to gather data from four different groups of participants: children of parents with severe mental illness (COPSMI), parents living with severe mental illness (PSMI), other caregivers of the child in the family (OCGC), and service providers (SP), to ensure including the experience of all family members and richness of the exploration. After finalizing the results, findings will be used to inform development and adaptation of the potential interventions as well as map the potential delivery system of the services. In addition, the study was also planned to be used as an advocacy opportunity to raise awareness on parental mental illness for both service users and providers. By inviting community mental health workers into the study, we planned to build a professional network so that, collectively, we could push the implementation of the supportive intervention forward in the next step. One of the biggest foreseeable challenges in further intervention implementation is likely to be the providers who will deliver the supportive service in a more accessible and regular basis to the families. So far, the community mental health workers seem to be the best fit to undertake this work due to their routine contact with families living with parental severe mental illness and the well-established community-based service system. However, they have limited time to take on

such an expanded role. Therefore, engaging their awareness and participation about parental severe mental illness is one crucial goal of this field study.

## **Part 2: Publishable Paper**

### **Understanding the Experience of Living with a Parent with Severe Mental Illness in China from Multiple Perspectives: A Qualitative Exploratory study**

#### **1. Introduction**

Over the past few decades, children and families living with parental mental illness have received growing interest from practitioners and researchers in a range of fields<sup>97-101</sup>. These wide-ranging researches have demonstrated the extensive effect of parental mental illness on family life and children's development and wellbeing both physically and mentally<sup>102-104</sup>. Studies have shown that children of parents with mental illness (COPMI) are three to seven times more likely to experience poor psychological outcomes and diagnosed psychiatric disorders<sup>105-110</sup>. They also tend to have a higher incidence of developing intellectual and learning disabilities<sup>111,112</sup>, emotional dysregulation<sup>113,114</sup>, problematic behaviors<sup>115,116</sup> and other psychosocial difficulties in childhood<sup>117-120</sup> and later life<sup>121-123</sup>. In short, a large body of literature has identified COPMI as an "at-risk" group due to their genetic inheritance (particularly with parental schizophrenia and psychosis)<sup>124,125</sup>, psychological vulnerability, poor family relationships, economic constrain, and other social-environmental disadvantages<sup>126-129</sup>. Several studies, moreover, suggest that a growing number of children in many countries are affected by parental mental illness<sup>20</sup>. For example, 20% and, in some cases, up to 50% of adults known to mental health services have dependent children at home in America<sup>131</sup> and Britain<sup>132</sup>, and about 1 in 4 or 5 young people under the age of 18 live in families in which at least one parent with mental illness in Australia<sup>133,134</sup>, in addition, estimated 450,000 children have parents with diagnosis of a mental disorder in Norway<sup>135</sup>. Therefore, given the growing significance of the issue, strategic support and systematic interventions are urgently needed to enhance the mental wellbeing of the next generation.

Fortunately, several evidence-based preventative programs have been developed and proven to be effective<sup>136–144</sup>, such as Let’s Talk about Children (Finland)<sup>145</sup>, Family Talk Intervention (US)<sup>146,147</sup>, and Young SMILES (UK)<sup>148</sup>. However, almost all these interventions were designed in high-income countries, where significant resources are available for mental health and social services. Little is known about children and families living with parental mental illness in resource-limited settings, such as China.

A pioneer project, named Care for Family 花园 (CAFF), was launched in 2018 by Peking University Institute of Mental Health in China. CAFF primarily focuses on children and families living with parental mental illness and aims to promote the functioning of these families and the wellbeing of these children. The efforts leading to this project can be traced back to 2004, starting with the largest national reform of mental health services in Chinese history<sup>149</sup>, known as the 686 Program after its initial funding of CNY 6.86 million<sup>150</sup>. A new service model integrating hospital and community treatment was introduced and implemented throughout the country to improve the accessibility and equity of mental health services. It primarily targeted the individuals with severe mental illness and, as a by-product, it has largely built the mental health infrastructure and workforce nationwide<sup>151</sup>. With the 686 Program<sup>152</sup>, more national and local policies were developed to allocate resources for strengthening mental health services, and innovative programs were undertaken to address the needs of patients with severe mental illness. (For example, free medication was provided to patients that would previously been confined with chains). In addition, the first law on mental health in China was enacted a few years later<sup>153</sup>. After these efforts, more and more patients were able to rejoin their communities, take part in social life, and consequently get married and have children.

This progress over a generation lead to a new task being assigned to the mental health professionals, addressing the needs of children and families living with parental mental health issues in China. CAFF was founded in this context. It started with a vigorous effort to advocate a focus on parental mental illness as the best way for professionals to provide mental health services. In the meantime, a series of workshops and training programs were organized to learn from international practice and strengthen professional competence on dealing with parental mental illness. Experts in the field were invited to introduce their experience and contribute to the exploration of contextually adequate and culturally sensitive service models for Chinese families.

Since 2018, CAFF has focused on raising public awareness about parental mental illness by sharing relevant information and stories in social media and enhancing the understanding of the issue through various activities. For example, national and local summer camps for families where a parent has a mental illness (FaPMI) were organized in all CAFF partner sites. It has now become apparent that effective interventions to make sustained improvement and to provide systematic support are urgently needed, given the high demand for these measures from the parents and families.

This study aims to illuminate the experience of living with parental mental illness in China from multiple perspectives and enrich the understanding of this issue. Hopefully, this will set the stage for studies of the feasibility of adapting evidence-based interventions for COPMI and FaPMI in a Chinese context. This study primarily focuses on families with severe parental mental illnesses, namely, schizophrenia, paranoid psychosis, bipolar disorder, and schizoaffective disorder, because these families are the most vulnerable and most in need of support due to the persistent nature of the symptoms and the severity of the impaired functioning and disruption of their family lives. Moreover, severe psychiatric disorders seem to be a marginalized area of

interest within the broader scope of parental mental illness. In fact, the majority of evidence-based interventions were initially developed for children whose parents had diagnosed mood disorders, mostly depression. Less is known about parents with severe mental disorders. Hence, this paper addresses this gap in the literature. Furthermore, the current community mental health service system in China is an extension of the 686 Program, which, fundamentally, was established for patients with severe mental illness. More systematic resources and data on mental health services are available to this group.

## **2. Methods**

This qualitative study was completed as a preliminary exploration of a larger project to adapt and implement targeted interventions for children and families with parents that have severe mental illness in China. The goal of the current study was to collect first-hand information from relevant personnel to gain insights on parental severe mental illness and use it to inform further actions.

### **2.1. Sampling and Recruitment**

A purposive sampling strategy was applied to maximize the variety of perspectives and ensure the depth and richness of the information<sup>154,155</sup>. Four groups of participants were identified as the best sources of information on the issue of parental severe mental illness: children of parents with severe mental illness (COPSMI), parents living with severe mental illness (PSMI), other caregivers of the child in the family (OCGC), and service providers (SP). Child participants consisted both of underage children and adult children who had lived with childhood parental mental illness, with a view to garner reflections on both present and past experiences. Participants were purposively selected for each group, taking into account their availability to attend the study

as well as their ability to articulate experiences and opinions. Snowball sampling was used in recruiting service providers.

The recruitment of participants was greatly supported by the psychiatrists at Peking University Institute of Mental Health (also known as Peking University Six Hospital) and their partner community-based service providers. The psychiatrists helped to introduce the study to prospective participants who previously visited or currently visit them, and to find the initial group of service providers from their professional network. Participants were recruited mainly from five municipal districts in Beijing: Haidian District, Chaoyang District, Xicheng District, Daxing District and Fangshan District. It covered a wide range of geographic areas, including both urban and rural areas of Beijing.

## **2.2. Data collection and analysis**

Data were collected through in-depth, in-person, semi-structured individual interviews. Different interview guides with core themes and suggested questions were pre-designated for each participant group. For child participants, two versions of the interview guides were especially prepared for underage and adult child participants, respectively, to make sure the content and language were appropriate for their age. Participants were asked to answer questions relating to their experiences and perspectives of living or working with parental severe mental illness as a child, a parent, a caregiver, or a professional. Moreover, opinions on disclosure of parental mental illness to children were particularly of interest in this research in light of a previous discovery of its significance<sup>156</sup>. The interview guides were initially developed in English and translated into Chinese for study use. A small pilot test of the interview guides was conducted with peer support

specialists and mental health service providers at the study site. The peer support specialists provided feedback on the appropriateness of the language used in the interviews.

All interviews were conducted in Mandarin by one researcher, who was a native Mandarin speaker with training in ethnographic work and qualitative data collection techniques. Interviews were conducted either in a private office in health facilities or at other participants' preferred places (e.g., home or office), where the privacy of the conversation could be protected. Two interviews were conducted a week apart, except in the case of service providers, who were interviewed only once. A total of 86 interviews were conducted with 50 participants (COPSMI interviews = 24, PSMI interviews = 28, OCGC interviews = 20, SP interviews = 14).

Shortly after the completion of each interview, the audio recording of the interview was transcribed using a digital recorder with a brief summary of key information and notes taken during the interview attached at the end. All transcripts were anonymized and double checked before analysis to ensure the accuracy of the transcription. Due to time constraints, transcripts were not entirely translated to English. Only the text used for the final report was translated.

Data were analyzed inductively using the content analytic approach<sup>157</sup>. First, all transcripts were systematically reviewed by the researcher and a subset of interviews from each participant group was selected as sample texts to develop a codebook, a preliminary set of abstracted codes. Then, the codebook was used as a reference tool and applied to recode all transcripts. This step largely reduced the irrelevant content to answer the research questions from interviews. Next, the coded data was categorized using a label, an elaboration, and an illustration, to identify important or repeated patterns and subjects. Last, these categories were grouped to form a broader concept capturing the essential themes in each participant group.

## **Ethical Approval**

The study was reviewed and approved by institutional review board at the Harvard University Office of Regulatory Affairs and Research Compliance (IRB19-0612) and the ethics committee at the Peking University Institute of Mental Health (2019-31).

### **3. Results**

#### **3.1. Characteristics of study participants**

**COPSMI.** (n = 12) Nine child participants in this study were female. Three were adult child participants, with two female and one male participants, in their middle age and had children themselves at the time of the study. The rest are children on average age of 13 years, ranging in age from 12 to 15 years, who were all in schools while participating in the study.

**PSMI.** (n = 14) There were equal number of male and female participants in the study. The mean age of the group was 40 years. Two of the participants were divorced and taking care of a child with the support of other family members. Nine participants had completed college-level education, including vocational school. Almost half of the participants were unemployed at the time of the study and three of them were working in the mental health support program at the community centers. Most of the participants had only one child, except one mother with two daughters. The age of children varied a lot, ranging from 6 to 30 years.

**OCGC.** (n = 10) Six out of ten other caregivers for children in the study were women. More than half of the participants were grandparents and the rest were the healthy parent of the children.

**SP.** (n = 14) Twelve service providers were women (only two community mental health workers were male). The mean age of the group was 37 years. The group consisted of seven community health workers, five psychiatrists from community health centers and a specialized hospital, and two social workers. Nearly three-quarters had completed University level education or above.

### **3.2. Overview of study results**

Data analysis yielded several main themes in each participant group. Representative quotations from the interviewees were included in theme descriptions and additional mini case studies were used for demonstration the living experience (except the service providers). Each participant group reported an important insight into the life of parental severe mental illness in China from their own perspectives and lived experience.

#### **3.2.1. Children of parents with severe mental illness (COPSMI)**

The overarching theme was identified as “living in skewed care”. The children were living with relatively good physical care but poor emotional support. Their emotional needs of relating to parents with severe mental illness were highly neglected and had profound impact on their development. Three themes grew out of data analysis: (1) impact of “not knowing”, (2) it takes a family to raise a child, (3) short-term and long-term impacts

##### **(1) Impact of “not knowing”**

***Seeking understanding.*** Children discovered parental mental illness that their families did not disclose to them. Many families wanted to keep it secret, however, there were various ways children got exposed to it in way that did not necessarily make sense. For example, children would overhear conversations or arguments of family members, observe suspicious behaviors of their

parents, or witness acute episodes of the disorders. Many reported that little or no information was provided by the parents or other family members regarding what the children had observed to explain what was happening in the families. It often caused misunderstanding, confusion, and frustration for the children, as a result, they arduously struggled to seek information to help them understand the situation. One stated:

*I found an article in WeChat talking about schizophrenia. Some descriptions were very similar to what I have observed on my mom. I knew there was something wrong. I started to do my own search on the internet. (16 yr., Boy, C12)*

**Protecting the caregivers.** The children were very sensitive and caring for their caregivers. Once they sensed something discomforting their caregivers, they would try hard to protect them from it. Moreover, they would develop their own ways to comfort and support the sick parent without being recognized by other family members. However, sometimes this could be problematic, as described in the interviews:

*I used to ask about this. But after I found my grandpa became very sad every time I asked, I stopped asking it anymore. (13 yr., Girl, C2)*

*I was worried of my mom. Thus, I did not want to go to school so that I could stay with her at home. (12 yr., Girl, C10)*

**Emotional burdens.** Child participants offered important details of how not knowing enough led to great emotional burdens on them. Fear, loneliness, distress, guilt, and regret were commonly described.

Feeling excluded by the family and a strong sense of loneliness were reported by several children. In the words of one:

*I am a member of the family. Why didn't them tell me what happened in my family? I did not know who I could go to talk about it. I felt so alone. (15 yr. Girl, C6)*

Fear was reported mostly experienced in early age of the children, and often when they observed fights between parents, conflicts among caregivers, and abnormal behaviors of the parents. In addition, sometimes, one parent had to be hospitalized in an acute episode and she/he ended up being missing for a couple of days to several weeks. Without appropriate explanation, children formed their own theories on what happened and often perceived the situation to be much worse than the reality. As one recalled:

*... my mom had some problems. She got upset so easily and started to quarrel with my father every time he said something wrong... I still remembered once my father was washing dishes, he just said there were so many dishes and they were so dirty. My mom started a fight immediately. I was very scared at that time. They mentioned getting divorce several times in their fights. So, I was so afraid that they would bring up divorce again this time. (12 yr., Boy, C5)*

Children described much less feeling of fear when they got older because they had gotten used to such situations and became desensitized. However, it is hard to say from the description of the children, whether it was an active adaptive response or passive rejection to the conflicts.

Feeling guilt or regret was brought out for different reasons. Participants reported feeling guilty for not being tolerant, reasonable, or supportive of the ill parents, when they did not know about their mental conditions. One described:

*I finally made sense of what happened to my father at that time when I developed mental disorders myself in later life and was sent to be hospitalized. After my symptoms stabilized, I started to help the nurses preparing posters in the ward. I wrote information about mental disorders on the poster from a book gave by the nurse. By reading those information, first time in these years, I understood what happened to my*

*father. I felt very regret. If I could know it earlier, I would treat him much nicer... He was sick. Overall, it was not his fault... (30 yr., Woman, C9)*

Moreover, some children felt guilty because they attributed the symptoms of the parents to their actions and blamed themselves for not being a good child, as one reported:

*I often got up late in the morning. So, we had to rush ourselves to go to school. My mom got so pissed off and yelled at me when it happened. Then my father started quarrel with my mom. He would ask my mother to let him send me to school. If I could get up on time and not to be lazy, none of these would happen. (13 yr., Boy, C7)*

## **(2) It takes a family to raise a child**

***Irreplaceable attachment.*** The need for the company of PSMIs and feeling loved by them were recounted by participants. Even when the parenting capacity of PSMIs was limited, what children needed was very simple:

*... I just wish my mom could see me. She could put some more attention to me. when I come back home from school, she could ask about my day. she does not need to do anything special. I just want to know she cares about me. (13 yr., girl, C3)*

Another child described her experience when her mother was sent away to be hospitalized:

*I missed my mom so much. I even cuddled my mom's pajamas when I went to sleep because I really missed her. But I did not tell anyone else. (12 yr., girl, C10)*

Children expressed different forms of need to engage their PSMI, however, feeling cared by PSMI was a fundamental need for them.

**Strong family support.** Most children have reported they were living in a big family with more than just their parents. Often their primary caregivers were family members other than PSMI. They did great jobs of taking care of the children's everyday activities, such as attending school. Even when the PSMI, to a large degree, engaged in parenting, the support they got from other family members was significant. The family system was well organized around the child in the best way they could to meet the developmental needs of the children, particularly the physical needs. One recalled:

*If I had any question about assignment, I went to my sister for help. She is older so she knew the answers... My grandma took me to school when I was younger every day. Now I could go myself. She only needed to prepare breakfast for me before I went to school every morning... Often, my grandpa went to the parents' meeting for me. (15 yr. Girl, C6)*

### **(3) Short-term and long-term impacts**

**Accelerated growth.** Early maturation of the children was a result of the complex and unique life experience of living with parental severe mental illness. Children were forced to grow up physically and mentally to carry more responsibilities and taking care of their "vulnerable" parents. However, this was more frequently reported in cases when there were no other family members providing support. One child living in a family with both parents experienced health difficulties, whose mother was diagnosed with schizophrenia and whose father had mobility problems, and was estranged from the extended family, described:

*I had to consistently worry and think about if my father was ok at home, if my mother got home safely from the rehabilitation center, what we should have for dinner and many other things. How could I concentrate to study? I was highly distributed in the class. I did not have time to write assignment when I got back home. (15 yr., boy, C4)*

Consequently, this early maturity had an impact on other aspects of the child, such as peer relationships:

*... I did not have friends at school. They (classmates) were too naïve to understand what I was saying. They often laughed at me and thought I was silly and crazy when I told them there were many dangers in life. I did not want to bother to explain to them. Also, I did not know how to explain to them. They would not be able to understand what I experienced anyway. (15 yr., boy, C4)*

***Impacts last to adulthood.*** The impact of parental severe mental illness did not stop when the children entered adulthood. It still played a significant role in their life as an independent adult, as a professional and even as a parent of their children. One recalled:

*When I got pregnant. I told myself I would do a better job than my mom. I would do my best to take care of my child. (30 yr., Woman, C13)*

### **A mini case study of an adult child participant**

Mrs. Wang was invited to the interview initially as a parent participant. She was diagnosed with schizophrenia at age 19 when she was in college. The interview took place in an office in the hospital during the weekend. Mrs. Wang showed up with her husband. During the interview, I found that she was a COPSMI, as her father had been diagnosed with schizophrenia when she was in middle school. Her experience of being both a child of a parent with severe mental illness and a parent with severe mental illness put her in a special position to understand the issue of parental severe mental illness. Thus, with her agreement, we arranged other interviews to share her experience as COPSMI in the following weeks.

Mrs. Wang was currently in middle age. She worked as a casual laborer in different places whenever she felt well enough to work. Her husband had a chronic condition, which also made

him unable to secure a job. Thus, they were living with their son in public rental housing and receiving state subsidies.

Mrs. Wang was a very talkative and enthusiastic lady. She was very open to sharing her experience as a PSMI from the beginning of our meeting and with a bright smile all the time. It was hard to imagine this was a person who experienced so much suffering and adversity in life. The interview about her experience as a parent felt relaxed and went smoothly. We both expected that her subsequent interviews as a COPSMI would be easy since we had already established a good relationship and she was comfortable sharing her life experience with mental illness.

However, to our surprise, it was not an easy one at all. Mrs. Wang experienced a strong emotional episode while she recalled her childhood experience of living with her father's schizophrenia. She told the story from the very beginning of her father's first onset. She described in detail how she was asked to leave school in the middle of a class and brought to the hospital. Later, she learned that her father committed suicide in his first onset and the families brought her to the hospital just in case there was a chance for her to see him if he could not make through. When she arrived, her father had already been sent out from the emergency room. Thus, she was not told what had happened. She still remembered vividly, after all these years, how scared and confused she was at that time. She did not know what was going on and why she was brought to the hospital. She could only sense that something very bad had happened. It was chaotic. She was brought to "here and there" and asked to stay with her aunt for a couple of days because her father needed to stay in the hospital to take care of her father. No more information was provided until many days later when she was brought back home by her mother. She did not learn that her father had committed suicide until many years later.

She also highlighted the helplessness she experienced when she found her mother was crying in the dark alone after they got home. She recalled:

*...I wished someone could support my mom. She was extremely lonely when my father was hospitalized due to suicide and mental illness. A lot of families have left us because of my father's condition. Only my aunt was willing to take care of me for my mom. I saw her crying and sitting in a daze night by night. She did not know where to seek for help.*

All those memories remain in her mind. She told me many of the details that she did not know until she had grown up and had her own family many years later. She wished she had a chance to talk about it and share her feelings and thoughts with her parents back then. She did not know if her parents realized how hard it was for her to go through this experience. They were understandably busy managing the illness and struggling to keep the family moving forward. Talking to their middle school daughter about what had happened and helping her to understand the situation seemed to be not on their list.

Mrs. Wang also reflected that the more she learned about mental illness over the years, the more she understood her father's "silliness" back in those days: being always downhearted, not taking care of the family responsibilities, but rather wandering around, and making trouble with others over nothing. She used to feel ashamed of this nonsense and, sometimes, blamed her father for being such a troublemaker for the family. For example, in some years, her father constantly quarreled about issues with the neighborhood committee out of nowhere. But the family actually got a lot of social support from the neighborhood committee. So she was very upset and sorry for his behavior. She knew her father was ill but did not fully understand that this trouble and embarrassing behavior were attributable to the illness. Now, when she recalled, she felt regret and guilt for not being more understanding of her father:

*... of course, I wish none of this (mental illness) happen[ed] to us. But if it will happen, I wish I could be explained and understand the situation as early as possible so I could do something to help. I felt very regret I treated him (father) so bad. He was sick. It was not his fault. I should take a good care of him. I felt so much guilt of not supporting him when he needed and even blame him of causing so many troubles. I did not have a good relationship with my father since then.*

Also striking was her description of the experience of stigmatization of her father because of his mental illness. He was often called “Wu Feng Zi” (武疯子, literature translation: madman with aggressive behaviors) by neighbors. It was a very belittling name, reflecting how people perceived an individual with severe mental illness as a lunatic and as dangerous. Children living in the neighborhood would keep yelling “Wu Feng Zi” around her when they saw her. Mrs. Wang recalled that, at the beginning, she refused to accept the fact that her father had developed a mental disorder. She thought it was an illness only for weak and timid persons, a perception that was also commonly shared by people at that time. She mentioned even there was no one saying dirty words in front of her face, people often closed their door and avoided contact with her family. She expressed a strong wish that there could be someone to help her to understand the mental illness and tell her how to react to the misunderstanding from others back then. It took a couple years for her family to recover from the impact of her father’s mental illness.

### **3.2.2. Parents living with severe mental illness (PSMI)**

Parenthood was described as an experience like a roller coaster with ups and downs. Even with tremendous individual, familial, and constitutional challenges, PSMIs considered parenting as a great gift in their lives. In addition, PSMIs demonstrated the experience of talking to children

about parental severe mental illness from their initial hesitations and what made it happen eventually. Analysis revealed four themes in the parenting experience: (1) inadequate support of PSMIs' parenting role, (2) downs of parenting, (3) ups of parenting, (4) experience of disclosure

### **(1) Inadequate support of PSMIs' parenting role**

***Tension among caregivers.*** Many parents described having difficulties in dealing with interpersonal relationships overall. The couple's relationship in itself was challenging for them, yet it got more complicated when the child took part. Typically, parenting was much more than the relationship with the child in a Chinese family; the child was a "hot spot" connecting various issues and people in the family. In our cases, as we learnt that in order to support COPSMI, other family members had to be largely involved in the parenting duties. Hence, tension among caregivers was commonly expressed as a consequence of disagreements on parenting and hurt COPSMI grievously. One parent recounted:

*Everyone in the family took part in parenting, my mom, my husband, and me. But my mom spent relatively more time with her (daughter) especially when I was not feeling well. Thus, it worried me to think there might be difference when grandparents took care of the child than the parents. (Mother, Bipolar disorder, P9)*

Moreover, several strategies the family used to deal with this tension were also mentioned in the interviews:

*We arranged a family meeting in a regular basis of every week to discuss things, for example on Saturday morning. (Mother, Bipolar disorder, P14)*

***Voiceless in parenting decision.*** As in many other experiences in life, individuals with diagnosis of severe mental illness were not taken seriously in decision making by others. Their

mental illness was perceived as reflecting negatively on their personal character, competence, and ability. Even when they took part in the parenting role, their opinions were often discredited, and disagreements were interpreted as a sign of their abnormality. Other caregivers expected PSMI to take care of the child according to their instructions, which they considered as more suitable to the “normal world” and better for the child development. One recalled:

*I had very different view on education and what is the best for the child development than my wife. I do not think getting high scores in school means everything. But my wife thought I understood nothing about the current situation and how competitive the world is after all these years staying at home. My daughter was not very good at math. My wife has signed up for two after-school classes for her. She was not allowed to play, even she finished her school assignments early. My wife would prepare additional tasks for her to do. She did not agree to the way my wife took all my daughter's time on study. Child should enjoy their time to be a child. It is precious. They would never have the second chance to experience it again.... My wife told my daughter not listening to me because I was sick. My daughter listened her mother more. (Father, Bipolar, P11)*

***Unprepared institutional support.*** A number of parents recalled the challenges they faced when they encountered social systems. One young mother told about her long bumpy journey to file a document for her pregnancy so that she could deliver the baby in a hospital, which is a standard process for any pregnant women in Beijing. Unexpectedly, this simple step took a large amount of effort and even special arrangement from the department of health. She was rejected by several hospitals because of her diagnosis of schizophrenia, the hospitals claimed that they were not equipped to take care of psychiatric patients. It seemed understandable from the safety point of view, but no alternative, no referral, nothing was offered to guide them where to look for help. She said:

*... we registered in the community health center. They called to check in from time to time. But we needed to look for hospital where to deliver ourselves. They did not assist on this part. It was all on our own... we went to several hospitals but none of them was able to accept me. We needed to look for a hospital having both obstetrics and psychiatric departments. Eventually we were assigned a hospital by a special arrangement of the department of health after my mom went to complain there for my situation. (Mother, Schizophrenia, P10).*

Several other stories told by PSMIs about their hard time dealing with schools or communicating with teachers captured a similar scenario. Families living with parental severe mental illness were invisible in the social system. Social institutions, such as hospitals and schools, were not prepared to provide appropriate support and services to address their needs.

## **(2) Downs of parenting**

***Low parental self-efficacy.*** PSMIs often reported low self-confidence about their parenting capacity during the interviews. They found that handling various situations with children and providing good care was much more challenging for them than for parents who were not diagnosed with severe mental illness. Many of the social and family responsibilities of PSMIs had been removed when they were diagnosed. They started to be treated as vulnerable and disabled, who needed to be care but not care for others. PSMIs heavily internalized these disempowerments and became used to self-doubt. Moreover, the previous removal of their responsibilities largely damaged their confidence and lower their self-esteem. Parenting was almost the biggest challenge they faced since they were diagnosed, and it brought tremendous responsibilities to them. one mother stated:

*I could become very annoying, unreasonable, having my own way of thinking, and not caring for others when I experienced onset... I did not know if I was capable to be a mother. (Mother, Bipolar, P5)*

Moreover, a feeling of weak parental authority over the child was highlighted as contributing to the low parental self-efficacy:

*I used to have an authority as mother to my child. But now I felt it was weakened. It maybe because she grew up now, maybe because she witnessed my illness. She saw my weak side and realized mother was not as powerful as she used to think. (Mother, Bipolar disorder, P14)*

**Concerns over the impact on children.** Many parents reported that they struggled a lot and hesitated to make the decision to have a child due to the concerns about the inheritability of mental illness and the impact of psychiatric medication on the baby. One mother recalled:

*When we discovered my pregnancy, I was not sure if I should have this child. I was concerned that I had been taking medication all the time and that may affect the baby. But he (husband) encouraged me to consult with my psychiatrist. ... Eventually, we went to different psychiatrists, pediatricians, and almost everyone we could ask for advices on this. (Mother, Schizophrenia, P6)*

One participant even said that her first marriage ended because of her ex-husband's overwhelming concern about the potential risk of inherited mental illness:

*My first husband, we got divorced because of my mental illness. He was concerned that I would not have a healthy child. My mental illness would inherit to the baby. (Mother, Bipolar disorder, P8)*

Moreover, concerns about being a bad role model for children and having a negative influence on them were raised almost by every parent participant. PSMIs worried that children might observe and learn from the residual symptoms of their mental disorders. They described a lack of clear guidance on how to minimize the impact of their symptoms on children and their anxiety that the problematic behaviors or issues of children were because of them. One mother reported:

*...I knew mental illness is not an infectious disease, but I still think it might be better that my child kept some distance from me. So, he will not be impacted by me. Who knows what impact I might have on him?*  
*(Mother, Schizophrenia, P11)*

*So far, there was no issue raised concerns on my child. She developed very well in all aspects. But I am just concerned about my emotions. Sometimes, I had bad day. I was in bad mood and felt anxious. I was very afraid that I would lose control over my emotions and made negative impact on the child. However, most of the time, I thought I was clam. I got upset easily only when she did not listen to me. (Mother, Bipolar disorder, P9)*

**Parenting resource-constrains.** Many PSMIs were not able to keep their jobs or find work anymore once they developed severe mental disorders. Even after recovery, their social activities and networks were significantly limited, in many cases almost to zero. They spent most of the time with families and stayed at home in social isolation. Their social circle became very narrow, and typically included only (extended) family members, people related to mental health (community health workers, peers in support group, psychiatrists) and maybe parents of their child's friends.

Moreover, some reported experiencing financial constraints due to lack of working opportunities or residual symptoms that prohibited them from work after recovery. A few families recounted the need for having an additional family member stay at home and take care of the PSMIs because of their severe impairment of functioning. It meant the family lost at least one to two job incomes to support the family. In short, PSMIs reported limited social and financial resources to support their children compare to parents who did not have mental illness. One mother described her desperation:

*I knew it would not be good for my son to stay at home whole weekends. But I did not have other options. Most of his classmates were sent to different cram schools or interest programs in the weekends. I found a*

*tutoring class nearby to have him enrolled once. But he did not like it and refused to go anymore after several sessions. It was waste of the money. Moreover, our place is very close to the suburban side, far from his school and most of classmates, because we could only afford the rent there. Hence, he did not know other children who could play together there... I tried to look for some free demo classes for him in the shopping mall near to us, so that he could take part in some more activities. But the opportunity was rare. I do not have many connections who could offer more information on such activities. (Mother, Schizophrenia, P13)*

Another participant reported:

*[interviewer: how did you share the parenting work?] I would say the father of the child gave in step by step as my condition continuously getting worse. He used to have a stable job and then started his own business. Now, he has regressed to only take care of me and the child. He turned down many opportunities just because of my illness. He didn't go [to work] because of taking care of me. (Mother, Bipolar disorder, P14)*

### **(3) Ups of parenting**

***Reconnecting to the children.*** Participants reported feeling of guilt for their absent parenting due to the mental illness. They were desperately eager to make up for their absence and rebuild the connection with their children. The levels of absence varied depending on the course of the mental disorders and, particularly, the recovery in emotional functioning, which restricted their ability to feel and express their love to the children. Consequently, it significantly damaged the parent-child relationship. One parent stated:

*Actually, I wash her face now. I know that she is already 13 years old, there is no need for my help on this. But I thought as far as I was capable, I would like to do it for her. It is not saying that I wanted to spoil her. But I was worried it was all because of me. I did not do a good job to keep myself clean when I experienced*

*the onset. I did not wash my face while the child stayed with me at her age of 3 or 4. So I thought she was impacted by my ill behaviors.... There was ten years I did not perform as her mother. I feel very guilty about it. (Mother, Bipolar disorder, P14)*

***A second chance in life.*** For many PSMIs, being a parent was in general a positive and meaningful experience. They appreciated their decision to have the children. Moreover, children were described as hope and light in many parents' life after the severe mental illness destroyed almost everything they had before. Raising a child found them a new direction in life. Subsequently, it motivated them to participate in a treatment and recovery process to get back their life. As stated by one:

*I took my medication on time and visited the psychiatrist regularly to prevent relapse. I felt quite satisfied with my life now. I could spend a lot of time with my child and watch her growing up. My daughter brought a new direction in my life. Not exaggeratively, the rest of my life, I have only two goals, one is to support her (daughter) to be whoever she wants to be and another... (Father, Bipolar disorder, P13)*

***Making use of the ill experience.*** Two parents explicitly reported they used their experience of severe mental illness as an educational opportunity for their children. Few other parents expressed the experience of severe mental illness brought unique perspectives and lessons into their life, which impacted on their parenting. One stated:

*I would tell these stories to my child and let her understand life is more valuable than anything difficulties she might encounter in the future. No matter what happens, even the most unacceptable situation, life is still the most precious thing above all. After setting up this basis, whatever I talked with her it was not a big deal. (Mother, Bipolar disorder, P14)*

#### **(4) Experience of disclosure**

***Parents holding back disclosure.*** Several cases were reported in the interviews of the parent holding back from disclosing their illness to their children. First, parents were often concerned that talking to children about the parental mental illness might put unnecessary pressure on them and potentially lead to harm, such as self-stigma. As parents, they wanted to try their best to protect the children from any potential risks. Second, fear of being looked down upon by their children and loss of parental authority was described. Third, not knowing how to talk about this issue with the children was a common obstacle reported. Fourth, the unpredictability of disclosure discouraged parents from talking to their children. Parents did not know how the children would react to this conversation. Fifth, several parents thought talking to the children does not make any practical difference, that it would not help the children or enable the children to help them. Thus, there was no perceived need to the children with the parental mental illness. Simply stated, it was not their business. Finally, a couple of participants conveyed that they have recovered with no remaining symptoms. They have turned to the next chapter of their life and see no need to reopen the issue of mental illness. It will not impact the children and therefore, they do not need to find out about it.

***Facilitating the disclosure.*** Speaking from the experience on disclosure, some suggested they just let nature take its course. Children discovered it themselves when they got older or organically over time. There was no intention to hide the parental mental illness, but no extra effort to facilitate disclosure. Several children of the participants found out about their parents' mental health conditions when the participants were hospitalized, and they were not told in detail about the process when they were back home.

In contrast, few parents reported that their children were provided with clear explanations and information to help them understand what happened. These conversations often happened after

the children witnessed dramatic symptoms or an acute episode of the mental disorder and were mostly facilitated by other caregivers of the child. The intent was to release the anxiety and reduce the impact of witnessing the parental mental illness on the children. Only one PSMI participant reported that she was the person that did most of the talking to the child. In some other cases, children were told about the parental mental illness to better navigate family life and reduce conflicts with PSMIs.

### **A mini case study of a father with schizophrenia**

Mr. Qian was in his very early forties. I was surprised by how many ups and downs he experienced at his age. He used to work for one of the biggest companies in the catering business in China before developing the mental disorder. His working experience sounded like a legend story to me when he told me about it in our meeting. He started his career as a waiter right after high school and ended up as second in command in the company within a 10-year time span:

*... you could image how much effort I put in my work. As a person with only high school degree, it was literately impossible to achieve what I did. I had to learn everything myself. I was working almost 24 hours per day without any breaks. I dedicated all my time and life to this work. Also, it was a good time. The country was developing rapidly. Everything was new and there were tremendous opportunities everywhere. I do not think I could ever do it again now... I could give you an example. Once we received a big project. I just rent a hotel holiday house and asked my team to stay and work together there. Everyone needed to give in their cellphone to protect the confidentiality when they entered the house. And we just worked crazy. I did not sleep even a minute in bed during the whole week. If I felt tiered, I just laid down in a coach. Eventually we got that project. This is just a snapshot of my daily life that time. You could image how stressful life I had... I experienced my first onset in a business trip. After two-day negotiation, I crushed in the evening reception...*

Listening to Mr. Qian, I easily felt how much he was proud of his career achievement. It was his milestone in life. But everything fell apart the day he experienced the first onset. Fortunately, his story did not end there. He was a tough person. He tried again after recovering. However, it was not too long until he experienced a relapse. The work he had was too stressful and not good for maintaining his mental stability. His family decided he needed to change his lifestyle and cannot live in the old way anymore. Since then, he has started what he calls his “retirement life”. Only thing he needed to do was to take care of himself. The responsibility of making money for the family was taken on by his wife. The housework and childcare were taken on by his mother. Nothing was left for him to do. There was a time when his daily schedule was wandering around and eating three meals at home. It was frustrating after a while for him to have this “zero stress” life.

Thus, instead of working, he found a new passion in life: his daughter. He started to spend a lot of time with his daughter. He took over the work of driving his daughter to school and picking her up. They spent time watching TV, doing schoolwork, and playing together. He established a very close relationship with his daughter. He told me that all his daughter’s friends envied her for having such a great dad. He sometimes hosted a party, took the children together to the park, organized fun activities for his daughter’s classmates to help her to make friends. While she got older, there were increasing challenging requirements for him. Mr. Qian even took lessons to learn new knowledge and skills so that he could equip himself to better support his daughter. His daughter had become the center of his life.

However, more and more conflicts were occurred between his wife and him regarding the child. Because of his experience with severe mental illness, he valued health and happiness more than anything for her daughter. He thought it was important for her daughter to choose her own

life. As a father, he just needed to accompany her in this journey and support her if needed. But his wife had very different opinion on this point. For her, achievement in school is essential for her future. As parents, they should push her more to study so that she could be competitive with her peers. Another huge disagreement was around disclosure of his mental illness. Mr. Qian thought they should tell their daughter about his mental illness and felt that there is nothing to be ashamed of. It is also a great educational opportunity for his daughter to learn about mental illness and to better take care of her own mental health. Also, she could be more thoughtful about life. However, his wife strongly disagreed with his opinion. She thought their daughter was too young to understand any of this. She wanted her daughter to have nothing to do with the mental illness. There is no need to put this burden on their daughter. In a lot of their disagreement, Mr. Qian was attacked by the argument that he had mental illness and abnormal thoughts, and therefore should not be listened to. Mr. Qian learned from his experience to avoid any argument since it would always end with him being accused of his mental illness.

### **3.2.3. Other caregiver of the children in the family (OCGC)**

It was a double challenge to be a child caregiver in a family living with parental severe mental illness. The caregivers needed to not only undertake the significant amount of parenting responsibilities but also navigate the parental mental illness for PSMIs. As the interviews were analyzed, three themes emerged: (1) caregiving crisis: overburdened and overlooked, (2) challenges to engage PSMI in parenting, (3) stakes of caregiving

#### **(1) Caregiving crisis: overburdened and overlooked**

**Compound family duties.** During the interviews, we found that more than half of the caregivers provided compound duties for their families, they took care of not only the child but also other family responsibilities. Very often, they were also the caregivers of the individuals with severe mental illness. It has been described as an exhausting and overwhelming job. Every day caregivers were buried in massive family tasks. Caregiving seemed become the only theme in their lives. Participants described:

*I am living with my husband, my mother-in-law, and my daughter's family. I am in charge of all the housework. Doing grocery shopping, cooking, doing laundry, and cleaning the room, that is all my works. It never ended. My work started from the moment I opened my eyes in the morning ... Since the time the boy was born, he became my duty. I need to take care of him day and night, almost 24 hours. Even though we all lived together with his parents, but they did not get involved and shared the work. (Grandma, O7)*

**Invisible efforts.** Caregiver participants reported received little recognition of their heavy day-by-day caregiving work from members of the families. Their efforts were often taken for granted and underappreciated. One recalled:

*They (the couple, wife was diagnosed with schizophrenia) did not like to ask my opinion. If something happens, they just decide themselves and do not tell us. Since we do not know what happened, we have no idea how to support her. However sometimes, she became so mad at us. We could not even understand what happened. We have helped her to take care of the child day and night. They never paid us anything. Sometimes I even had to give her some of my money since she did not have a job. I dedicated all my effort to help her, but she turned her back to me whenever she wanted. It made me panic all the time. (Grandma, O4)*

**Lack of support to supporters.** Many caregivers reported they often experienced loneliness, for which three major reasons were proposed in the interviews. First, endless family

responsibilities occupied all the time and energy of the caregivers so that they had no personal life or social network. Second, due to the stigma around severe mental illness, caregivers reported that they hesitated to talk about their lives with others for fear that people would gossip about their family situation. Thus, they had to carry on keeping all the worries to themselves. Third, we found there was lack of system support at large. Caregivers described their feeling of powerlessness to deal with the adversities of the family and desperation of not knowing anywhere or anyone to look to for help. Some private services were mentioned, however, with unaffordable pricing for these families.

## **(2) Challenges to engage PSMI in parenting**

*Lack of feasible alternatives.* Keeping the children away from ill parents and taking over their parenting responsibility are neither in the best interest of the children nor of the PSMIs. During the interviews, we discovered that most caregiver participants even agreed with this, but in reality, the parenting role of the ill parents was nearly substituted. Engaging PSMIs in parenting often required additional assistance from other family members and sometimes professional support, for which a lot of resources and efforts were needed. That is added fuel to the fire, as many families living with severe mental illness already struggled greatly with constraints on resource due to the burden of disease. Without much resources to investigate alternative solutions, this was, so far, the best they could do. One described:

*I learned from one counselor that I should encourage him (father with schizophrenia) to play with the boy and to create some opportunities for them to interact. But I already have so much to do, taking care of the kid and other housework, and working for our living. I do not have that energy and time for it. No one else could help me. (Mother, O2)*

***Lack of understanding of parental mental illness and its impact on parenting.*** Lack of targeted information and practical guidelines on parental mental illness were commonly described by the caregivers. They reported having a hard time understanding the behaviors of PSMIs and gaining any confidence of their parenting capacities. Hence, instead of letting the risks fall on the child, they preferred to do everything themselves. One described:

*... She (mother with schizophrenia) just went out herself. If he (father) has time, the couple would go to park together and left the child at home. Of course, I could help them to take care of the child. But how could a normal parent go out to have fun themselves without the child. (Grandma, O8)*

***Balancing support and care.*** Caregivers struggled to balance the support to PSMIs as parents and care for PSMIs as patients. For instance, a common concern raised was that parenting responsibilities might expose PSMIs to too much work and stress, ultimately increasing the risk of relapse. To protect the patients, caregivers would take over the works from them as much as possible. On the other hand, to support PSMIs in their parenting role, caregivers needed to allow them to take on increasing parenting responsibilities. It was extremely tricky for many caregivers to keep this balance, as described:

*It was tricky to ask her (mother with bipolar disorder) to assist me on taking care of the child. She felt tried quickly after playing only few minutes with the child. I did not know if I should ask her to continue or take a rest. (Grandma, O8)*

### **(3) Stakes of caregiving**

***Embedded responsibility.*** Participants demonstrated a strong sense of duty when talking about what kept them continuing caregiving work. They reported that never had second thoughts

about providing care for their families. “It is my responsibility” was a sentence repeatedly said during the interviews. One described:

*She is my wife, the mother of my child. That is my son. It is my responsibility to take care of them. (Father, O7)*

**Children as hope.** Caregivers described the child as a hope in a haystack of adversities. Thus, how much hardship they have to struggle through, they would try their best to create a healthy environment for their children. This idea kept them moving forward, however meanwhile, it escalated the alarm of protecting children from negative influences of their ill parents.

*I just hope he could grow up safe and well. He is my hope. No matter how much I struggle for life, I try my best to create a good environment for his growing. (Mother, O2)*

#### **A mini case study of a father and husband whose wife diagnosed with bipolar disorder**

Mr. Xu was a tall middle-age man. His wife was diagnosed with bipolar disorder almost ten years before they got married. Even though she still experienced onset from time to time, her situation was stable most of the time, and no remaining symptoms disturbed her normal functioning. They were living together with their son and mother of Mr. Xu’s wife. Mr. Xu was very serious about our interviews. Once, on entering the room, he took out a big notebook and told me that he did some preparation for this interview. He wrote down all important information and thoughts in case he forgot to mention them during the interview.

Mr. Xu first stated that he used to serve in the military for many years before being discharged and now works in a management position at a research institution. Even though he was very busy with work, he kept eyes on his wife to ensure she is well. For example, she needs to take medication three times a day. Mr. Xu would send text messages to remind of her the time for

medication and ask her to text back every time she took them. Moreover, when he had to go for a business trip, he would always make sure that she could reach out to him anytime, even in the middle of the night. “If she couldn’t find me, she will feel unsafe” said Mr. Xu, “It is my responsibility to take good care of her because she is my wife. And now, she is not only my wife but also the mother of the child.” Mr. Xu told me that he thought it is important for the child to have healthy parents and a stable family. If the situation of his wife is not stable, he worries that it would put pressure on the child to think my mother is sick and not normal. He expressed that it did mean a lot of work for him. But for the best of the child, he never felt tired of doing it. Also, thanks to his military training, he is tough enough to handle all these challenges.

Moreover, Mr. Xu said his wife loves their son so much. He could tell she had tried her best to take care of him. However, due to her mental illness, sometimes it was challenging for her. She had no idea what to do once the child started to have difficult behavior. Also, she lost her temper easily when the child did not listen to her. For example, they often read bedtime stories before the child went to sleep and decided on the number of stories to be read. Yet, if he refused to go to sleep and bargained for playing longer after listening all the stories, she would get very upset. Mr. Xu thought it was normal for a child to behave that way and easy to handle. But his wife got annoyed a lot in such situations. Usually, at this time, he would take over from her and let her to get a rest to calm herself down.

#### **3.2.4. Service providers (SP)**

The overarching theme was summarized as “service blindness”. The health service system was not emphasized on and equipped to delivery of services and supports for families living with

parental mental illness. It was further refined in three themes: (1) inconsistent professional advices, (2) system readiness, (3) potential barriers of service delivery

### **(1) Inconsistent professional advices**

***Pessimistic protector.*** Some health service providers admitted that they would not recommend their patients to get married and even have a child given the current marital instability in the whole society. They described low confidence on the marriage of the patients and high suspicion of the intention to get married to a person with severe mental illness. They reported that they had heard many cases about person with severe mental illness being dumped or abused by their partners after taking advantages of the marriage. Many eventually ended up on the street or left in the hospital without any chance to go back home. In the words of one:

*Nowadays, even a great number of normal people could not find a partner and get married, many leftover men and ladies. Who would marry to a person with severe mental illness? (CMHW, S4)*

***Risk aversion.*** Some service providers considered marriage and parenting as potential risk factors for fluctuation of the mental disorders or troublemaking. They concerned the ups and downs in relationships may trigger relapse and destroy the recovery achievement of the patients. Besides, having another child with mental illness, which was highly possible due to the inheritability, would be unbearable pain and burden added to the families and caregivers. As described:

*Getting involved in intimate relationship increases the chance of relapse. Actually, several of my patients experienced relapse in the past because of it. I told them it was not a good decision, but they did not listen to me. When relapse happened, it took really long time, a couple of years, to recover. (CMHW, S5)*

**Essential step of recovery.** Some service providers described very different opinions regarding this issue. They encouraged their patients to experience intimate relationships and parenting, which they considered them as important steps of recovery and rejoining the society. Moreover, it could extend the supporting system of the individuals with mental illness and create new meaning and goals in the lives. One said:

*I think it is normal their desires get increased while their recovery progress. Everyone has a desire to have a better life. That is the same for the patients. When they are in better state of mental health, of course, they want more in lives, having a partner, getting a job, and having a child. (Psychiatrist, S7)*

## **(2) System readiness**

**Service priority.** Psychiatrists mostly are in the hospitals and provide diagnosis, various medical interventions, and clinical advices to people with mental illness. While CMHWs often serve in the community health facilities and are more oriented to assist the functioning recovery of the patients and policy related works. Even they were assigned to offer different supports, both reported predominant focus on the individuals who had the diagnosis of mental illness and their symptoms management. The need for supportive service to other people living with mental illness, such as their caregivers and children, were often observed but neglected due to the patient-focused service model. As recounted:

*Very little we knew about the children. Mostly we focused on the patients. Sometimes we may put some attention to the caregivers if we have additional time. But we rarely pay attention to their children in our work. I have never talked with the children of my patients, even when I visited to their home and see the children. (CMHW, S2)*

**Work overload.** Nearly all participants, especially CMHWs, described burnout by increasing work tasks as well as massive paperwork and administrative requirements. Consequently, it significantly cut down the time they could spend with the service receivers and support they provided. Children and families who were not the primary service target were always left out of attention.

*Now, the mental health work is getting heavier and heavier. Every year there are new tasks added without any additional support or stuff. We need to do a lot of paperwork. It is almost impossible to finish everything in a high quality [way], therefore, you need to know what to prioritize and attribute your energy to more important task. (CMHW, S1)*

**Low professional competency on parental mental illness.** Very few psychiatrists and CMHWs had training background or previous experience with children and parenting support. Hence, even there is no doubt that children and families living with parental mental illness need for support, participants often reported they were not competent to do that and recommended child service providers or other professionals who specialized in children and family to deliver such service. Yet, they could be part of the team to introduce and refer children and families to the service. Recalled:

*I do not think I am capable to provide help to these children. I did not have any previous training about children. I think such professional task should be done by professional people. (CMHW, S3)*

### **(3) Barriers of service delivery**

**Complex family dynamic.** Service providers reported the mix of diverse family dynamic with parental mental illness led to further complexity on the service delivery. For example, over-controlling parents were increasingly observed in their work with patients who had diagnosis of

severe mental illness. In these cases, families would probably not take part in the service to support PSMIs on their parenting role. Stated:

*I had a patient with schizophrenia and his mother was around 80 years old. This patient stayed at home almost all the time. His mother would go grocery shopping and bring a basket of food to him every week. ... We tried to persuade her not to do it for him and he was capable to do it himself. But she told me it was ok for her. She would do it for him as long as she could. (CMHW, S3)*

***Stigma around mental illness.*** Parental mental illness was still a secret among adults in many families. Service providers learnt various concerns of families and patients on talking about parental mental illness to their children rooted deeply in the stigma around mental illness. Keeping children away from issues related to mental illness were considered as the best protection by many families. As recalled:

*One boy discovered his father's mental illness at the time he applied to join the military service. All these years, the families have been hiding it from him. He was told that his father has some health concerns, so he could not go to work and had to stay at home to rest. Also, he has low IQ. This was how they explained to him. They thought intellectual retardation was more acceptable than schizophrenia. ... They warned all the relatives and neighbors not to tell the mental illness of the father to the boy. (CMHW, S2)*

*On one hand, they probably refuse to talk about it for the purpose of protecting their children. They might think if they do not talk about it, their children will be insulated from the mental illness. On the other hand, as I understood, they might think if they told the parental mental illness to the child, the child would think themselves were inferior to others. The child might think they were different to other children since their mom or dad were patients of mental illness. Because the patients often felt they were inferior to others because of the mental illness, they might think the child would have similar ideas. Also, they might be afraid that the child would look down on him/her and become disrespectful, like the father I told you came back*

*from US. He told me his daughter became disrespectful to him after she knew about his mental illness. (CMHW, S3)*

***Instability of service providers.*** Parental mental illness was not an easy topic to discuss for families and individuals with severe mental illness. It often occurred on the basis of a trust relationship. High mobility of the current health and social service system had significant negative consequence on building this relationship. One described:

*They (families living with severe mental illness) would seek for help if they established good relationships with the service providers. It took time for them to trust you. However, the service providers in community facilities are even less stable. There is even higher turnover rate there. Too fast. (Social service provider, S10)*

***Titular service.*** Service providers raised a practical issue in the current service system. Due to the constraints on human resource and budget, some services existed in name only, especially those required high professional competence but with low financial values, as described:

*The new service was added into the performance measures, but in fact, no one was doing the real work. It existed in name only. They just put the service framework up. (CMHW, S4)*

***Benefits at a cost.*** It was an unspoken shared understanding among service providers and patients that the current service for individuals with severe mental illness were also designed to serve a purpose of risk control and violence prevention. Patients hesitated to receive those service due to their fear of its disruption in other part of life and threatening to their privacy. When it came to the children, families would be far more protective. The fear of having impact on children's life and future would be a great obstacle to get involved in the service:

*The major group in our current service is older people, mostly above age of 50. At that age, their experience of stigma dropped to almost nothing so that they would receive our service.... However, for those patients for example, around twenties, they will have study and work in the future. If they register in the community [mental health system] because the system is connected with other departments, especially the police system. thus, they are extremely cautious of receiving the service. (CMHW, S1)*

## **4. Discussion**

### **4.1. Key findings**

Our study provides detailed insight into the experience of living with parental severe mental illness in China from multiple perspectives: COPSMI, PSMI, OCGC, SP. Clearly, evidence from the inductive analyses has shown both commonality and uniqueness of the experience in Chinese families comparing to the findings in previous studies.

#### ***Commonality***

*Open conversation with children on parental mental illness.* It was found that adult caregivers of COPMI, PSMI in particular, often faced with huge dilemma of disclosing or concealing the parental mental illness. These decisions have critically impacted both parents, children and their relationship. Concerns about negative impacts of disclosure on children were repeatedly brought out during the interviews with different adult caregivers, which were predominantly rooted in the stigma around mental illness. Avoiding children's encounter with mental illness was largely perceived as a way to protect the children. However, from the interviews with child participants, clearly it only led to counter-productive results, confusion, misunderstanding, various emotional burdens, and even sometimes the impacts lasted to the

adulthood, which is highly consistent with previous study findings across contexts and diagnosis of the parents<sup>158-162</sup>. Despite the absence of negative consequences of not knowing, benefits of disclosure were convinced clearly from the voices of children. By getting proper information about parental mental illness, it helps them better navigate and cope with life in more effective ways<sup>163,164</sup>. Moreover, this attitude of secrecy could also embed into the minds of children, which imperceptibly, reinforces the stigma about parental mental illness resulting in additional emotional burdens to the children. One study emphasized that children are aware of their parents' difference even long before they could articulate the issue of mental illness<sup>156</sup>. They observed the abnormal situations of their parents, however, as the researcher stated, struggled with intense confusion as they tried to make sense of what happened with limited information. "A culture of secrecy" distinctly portrayed the process that children were confusing and emotionally overwhelmed by the encapsulation of parental mental illness in the family, yet meantime, "inherited" this attitude to maintain this family secret from their experience.

*Parenthood consisting both challenges and rewards.* Experience of parenting for PSMIs reveals both frustrations and pleasures. This finding is similar to experience of parenting and parenthood in general, which often comes with tremendous ups and downs. However, on top of that, being a parent carrying on severe mental health challenges, added additional source of difficulties and sense of hope into this experience. This description was found in common for both mothers and fathers with mental disorders<sup>165</sup>. Frustrations often found associated with limited capacities due to the constraints of mental disorders itself, such as low motivation and energy level<sup>166</sup>, as well as low parental self-efficacy. In addition, engaging in parenting was also commonly found as a protective factor that motivate patients with mental illness participate in recovery process<sup>167</sup>.

*Inadequate support.* Inadequate institutional and service support from the current social and health system to meet the needs of children and families living with parental mental illness were found in this study and also widely studied previously<sup>168,169</sup>. On one hand, from the perspective of the professional mental health and care providers<sup>170</sup>, a common struggle was raised that they do not feel prepared and competent to provide support to these families and address issues of children. This reflection was proposed in both high-income country, like Australia<sup>171</sup>, and less-resource country, like China in this study. Several factors contributable to this challenge could be summarized as lack of relevant professional training on parental mental illness, poor organizational support to workforce, poor awareness on the issue of parental mental illness, inadequate resources and lack of target service and system design for parental mental illness. Particularly, in adult psychiatry service<sup>172</sup>, service providers are extremely unfamiliar with handling the issues about children. In addition, in many countries where have already developed and implemented target service system to address parental mental illness, used to experience similar hard time initially. On the other hand, from families' perspective, it often reported huge barriers to access care and dissatisfied experience in mental health and social service.

*Caregiver burnout.* Caregiving crisis was not a surprising theme came out in this study. The primary caregivers for children are mostly grandparents and the healthy parent. The hardship experienced by caregivers imbalanced with their contributions to the family was found in the current study. Similar result was also found in the study in Australia<sup>173</sup>. Lack of recognition and support to these informal care forces were issues largely raised globally, arguably, even more challenging for caregivers in the families living with parental severe mental illness. However, increased advocacy efforts and programs to support caregivers in their duties were promoted primarily in the developed countries<sup>174-177</sup>.

*Long-term impact to adulthood.* From the description of adult child participants, we gained some insights on the long-term impacts by growing up with parental severe mental illness, which is in consensus of previous studies highlighted impacts on two aspects of life, interpersonal relationships and mental health related issues in both positive and negative effects<sup>178-181</sup>. Friendships, intimate relationships, and parent-child relationships are critical interpersonal relationships in one's adulthood, which have found impacted by the childhood experience of living with parental severe mental illness<sup>182</sup>.

### ***Uniqueness***

*Family care for children.* Unlike the findings in previous literatures<sup>183,184</sup>, it was commonly found that strong family support in Chinese families prohibited the COPSMI to take over family responsibilities for their ill parent or even become caregiver of their ill parent. Family members well organized themselves to support the children and substituted the parenting jobs covering the absence of PSMIs. Children were, to the greatest extent, treated as children in their age and left out of the issue of parental mental illness. Only in the case that family support system is not strong prior to the parental mental illness, children had to take on additional family responsibilities. However, by increasing social change in family structure in China, the support to children has taken up to an increasingly high level.

*Lost opportunity for parenting.* Fear of losing custody of their children by disclosing parental mental illness was reported as a major obstacle for PSMIs in in Australia and US<sup>185</sup>. Abusive parent-child relationship and increased risk of mistreatment and neglect on children were often associated to the parents with mental illness, which is another actualization of stigma on mental illness. This fear significantly cut down the probability for these families to look for help

when needed. However, issue on child custody was not mentioned at all in the current study relating to the different child protection system in China. However, the fear of losing the parenting opportunity and strong wish to engage in parenting were expressed explicitly by the PSMIs in the study.

## **5. Limitations and Strengths**

We recognized the limitations of our study in both methodological and operational levels. Methodologically, participants were purposively selected to include people who could illustrate their experience in an articulate, expressive, and reflective manner, to ensure the richness of the information. In the current study field of severe mental illness, participants with those characters may represent certain circumstances. For example, for PSMIs, it may mean they were better in the symptom management and functioning recovery with more engagement in family responsibility, like parenting. Partially, it served the purpose of the study, in order to better understand the parenting experience of the PSMIs, they need to function well enough to participate in parenting and demonstrate the experience to the interviewer. Yet, it only showed the experience of a group of PSMIs and cannot reflect those who were more severely challenged in their parenting role or trapped in their illness. To tackle this limitation, we did not invite more than one participant, (children, ill parents, and other caregivers) from the same family unit. which the children and other caregivers may add to family experience of the more troubled PSMIs, needless to say the information from SPs. Moreover, content analysis as an analytical approach provided a useful way of summarizing and representing the substantial experience. However, an essential step of this approach is data reduction, which means that some data were not incorporated into the themes and details and the essence of the complexity were left out from the findings. Hence, a mini case study was attached in the end of each participant group as a supplement to the findings.

Another limitation might be the participants who took part in the study may have been generally more receptive to the issue of parental severe mental illness than nonparticipants. On the other hand, participants were, in various ways, related with the psychiatrists in the hospital where the research team located. There might be pressure on what information to disclose to the interviewer. SP participants who were referred by their colleagues or supervisors could also experience the same concern. Confidentiality was particularly emphasized in the beginning and throughout the interview to address this concern. Plus, most participants were interviewed more than one time so that a more trustful relationship could be developed, and participants could feel comfortable to share their personal experience and opinions.

However, in spite of these limitations, we consider the study a pioneering exploration on the issue of parental severe mental illness in Chinese family. One strength to consider is the inclusiveness of the study. To our knowledge, this is the first study which took in multi-angles to picture the experience of living with parental severe mental illness. Moreover, the variety of participants in each group intensified the richness of the description relating to the experience. For example, both retrospective reflections of childhood experience and present moment living experience were collected from child participants, in addition, both mother and father who had diagnosis of severe mental illness were recruited in the PSMIs group. Additional strengths were that most participants were interviewed twice, which gave a deeper insight of the participants' experience.

## **6. Implications and recommendations**

The findings indicated very important tips on parental severe mental illness of Chinese families, which oriented the further action-taking. First, children need to be well informed about

their parental mental illness with appropriate and adequate information. Set against the concerns on disclosure, there is significant greater short-term and long-term benefits to have open discussion on parental mental illness with children in the family. Very importantly, disclosure supports the social-emotional need and development of the children. On the other hand, children are smart enough to figure out themselves nowadays with the help of internet and massive social medias. Discovery has become more and more inevitable. It is better for children to be told by their families than misled by information from unknow source somewhere. Second, having PSMI play the role as parent is critical for both parent and the child. The role of PSMI cannot be replaced. Instead of removing PSMI from the life of the child, supporting and empowering them to engage with the child could be a better protection for both. In addition, engaging PSMI in parenting could also potentially release the burden on the other caregivers. Third, clear systematic information and evidence-based guidance on parental mental illness are neither available for service providers nor the families. It is urgent to fill this gap and enhance the shared understanding on parental mental illness among professionals and caregivers. Fourth, given the extent of the engagement of other caregivers in the parenting role, intervention or supportive service should also consider the needs of the other caregivers. We often found that parents with severe mental illness were found often lived in a big family unit so that other family members could provide support to the children and other family work. Thus, it is critical to improve the understanding of the other family members and engage them in the services to get family buy in family to buy in for the potential intervention. Finally, the current social and mental health service system are not adequately prepared to deliver such intervention and service to COPMI and FaPMI due to the existing constrains in the system and poor recognition of the significance of parental mental illness. However, the need and benefits of supporting children and families living with parental mental illness were increasingly

emphasized to the frontline service providers. More advocate efforts and data collection on these group in China are needed for raising the public awareness and promoting the system change.

## **7. Conclusions**

More studies on parental mental illness in China are urgently needed with data demonstrating evidently the significance and increasing the understanding of the current situation. Hopefully, this increased evidence and knowledge will promote the development of the targeted interventions and support services for these families, and subsequently help with dealing the adversities caused by parental mental illness and nourish the development of the children. Importantly, the voices of people living in parental severe mental illness and frontline service providers who directly work with those families ought to be brought onto the table and to take a place in decision-making. Research could be used as an opportunity to advocate and foster system change as well as empower and engage the powerless, especially in the resource-limited field of mental health care delivery.

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