


BMJ Open Access to family resources by families living with schizophrenia: a qualitative study of primary care workers in urban Beijing, China

Meirong Wang,^{1,2} Lifan Chen,³ Juan Tang,⁴ Yun Wei,¹ Guanghui Jin,¹ Xiaoqin Lu¹ 

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¹School of General Practice and Continuing Education, Capital Medical University, Beijing, China

²General Department, Beijing Chao-Yang Hospital, Capital Medical University, Beijing, China

³Department of Education, Xuanwu Hospital, Beijing, China

⁴General Practice, Gong He Community Health Service Center, Beijing, China

Correspondence to

Professor Xiaoqin Lu;
cumsfmxq@ccmu.edu.cn and
Dr Guanghui Jin;
jgh_04@sina.com

ABSTRACT

Objectives This study aims to investigate the access to family resources by families living with schizophrenia from the perspective of primary care workers in Beijing, and provide evidence for appropriate and effective family resource coordination in primary care.

Design Qualitative research using individual in-depth interviews to identify the access to family resources by families living with schizophrenia from the perspective of primary care workers.

Setting This study was conducted from September to December 2021 in six urban community health service centres (CHSCs) in Beijing, China.

Participants 3 general practitioners and 10 mental health doctors selected by purposive sampling method from 6 CHSCs in urban Beijing were interviewed.

Results Five themes emerged from the insights of the primary care workers: most family resources are non-targeted for families living with schizophrenia, the publicity of family resources is difficult, burdensome application process of family resources, limited available community-based treatment options and stigma hindering effective communication between families and society.

Conclusions It is necessary to simplify the application process of family resources and provide primary care workers with systematic training regarding family resources. More family resources and improved public attitudes should be promoted for patients with schizophrenia and their caregivers.

INTRODUCTION

Schizophrenia is a major mental illness affecting the normal functioning of brain. Severe impairment of functioning related to schizophrenia can be observed in daily living, family life, social interactions and employment.^{1,2} In 2022, the WHO estimates that schizophrenia affects approximately 24 million people or 1 in 300 people (0.32%) worldwide. This rate is 1 in 222 people (0.45%) among adults.³ There were approximately 16 million patients with mental illness in 2019 in China, of which patients with schizophrenia accounted for about half,

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Primary care workers have better understanding about the mental health service system.
- ⇒ A descriptive approach was chosen because it would directly and pragmatically show primary care workers' inner thoughts.
- ⇒ The study relies on secondhand perspectives from primary care workers rather than families living with schizophrenia.

and the incidence of schizophrenia in urban areas was significantly higher than that in rural areas.⁴

Family resources, including family and social support from peers during the course of psychiatric rehabilitation in schizophrenia, are vital for improving treatment effectiveness and controlling symptom progression.⁵ The rehabilitation of patients with schizophrenia is mostly supported by their family members in community.⁶ Based on the social drift theory, schizophrenia induces and exacerbates poverty by depriving one's education and employment opportunities, increasing medical costs, as well as creating isolations for people with schizophrenia.⁷ Burdens of schizophrenia on family, including physical discomfort, disturbed routine habits, tension, violence, chronic sorrow, enormous stigma, role changes, social withdrawal and financial/career difficulties, are substantial, particularly for middle-income countries due to limited family resources.^{8–13} Sufficient family resources are essential solutions to alleviate the burdens of families living with schizophrenia,¹⁴ improve the patient's family atmosphere, enhance family dynamics and facilitate the patient's recovery process. Family resources such as family-to-family support programme, psychoeducation programmes and mutual support groups for

family caregivers in developed countries impact family cohesion, family connectedness, family resilience, family hardiness and relationships in a positive way.^{15–17}

The Office of the State Council of the People's Republic of China promulgated 'National Mental Health Work Plan (2015–2020)' in 2015,¹⁸ which stated development plans of increasing the publicity of mental health, training more mental health professionals, decreasing the societal and economic costs of disruptive behaviours by individuals with mental illness and standardising the management of mental health service, etc. People with schizophrenia, as disabled, are qualified for preferential policies by the government, such as children's tuition reductions or subsidies, vocational rehabilitation labour programmes, legal assistance, etc.^{19–25} However, previous evidence shows that the awareness and utilisation of family resources are low among families living with schizophrenia in China.^{26 27}

As the capital of China, there were 79 000 people with severe mental disorders in Beijing in 2019,²⁸ most of whom were patients with schizophrenia. General practitioners (GPs) play a significant role in mental health-care at the community level and communication between policy-makers and patients, as well as coordination of family resources for vulnerable families. This study aimed to explore the access to family resources by families living with schizophrenia from the perspective of primary care workers in Beijing, and provide evidence for health professionals regarding appropriate and effective family resource coordination.

METHODS

Study design

Individual in-depth interviews were used for the exploratory aims of the study. A semistructured interview guide was developed based on existing literature and revised by experts of related areas to ensure that key questions were asked towards all participants, meanwhile allowing the flexibility to follow-up novel information.

Research team

The research team consisted of professionals with different backgrounds, including a professor and an associate professor in general practice, two GPs and two graduate students. The interviewer and data collection researchers received training and supervision in conducting qualitative interviews.

Participants and recruitment

There are six urban districts and ten rural districts in Beijing. The six urban districts had 10.988 million people, accounting for 50.2% of the long-term resident population in Beijing in 2020.²⁹ A community health service centre (CHSC) was selected from each urban district by random sampling. We purposively sampled primary care workers from the urban districts with a mix of sexes, ages and years of experience. Inclusion criteria were GP or

mental health doctor, and managing patients with schizophrenia. Written informed consent was obtained from each participant prior to the investigation.

Data collection

Face-to-face individual in-depth interviews with primary care workers were conducted from September to December 2021 by two interviewers in a meeting room. The participants were informed about the purpose, procedure and contents of the study.

Predetermined topics were chosen by the research team to elicit, in an open-ended fashion, an exploration of primary care workers' perspective. The topics included the factors affect the use of family resources by patients with schizophrenia and their families, and the difficulties in managing patients in community (see online supplemental file 1). Participants were informed that the whole interview could be completed in 30 min. The interviews ranged from 30 to 90 min in length, most of which lasted for approximately 1 hour.

Data analysis

All interviews were audiorecorded with consents from participants. Digital recordings were stored in a secure system. Audio-taped data were transcribed verbatim. Transcripts were reviewed and analysed by six members of the research team. We conducted content analysis^{30 31} by analysing the transcripts and identifying specific meanings and potential implications, in accordance with the topics. The research team members read the interview records carefully, extract important statements, encode recurring and meaningful content, collect encoded views, write down detailed descriptions, distinguish similar views and subliminate theme concepts, return findings to the participants to verify ambiguous information, and then reconstruct the data and achieve consensus based on discussion among team members. No new themes emerged in the analysis after the 13th interview, data saturation was considered, as the 14th and 15th interviews only added minimal information.³¹

Patient and public involvement

There were no participants and patients involved in the design of the study.

RESULTS

Characteristics of primary care workers

Thirteen primary care workers (overall age range, 30–52 years; mean, 39.38±6.41 years) from six urban CHSCs in Beijing were selected for interview. They represented a wide range of work experience (range, 3–30 years; mean, 14.69±7.48 years), and there were 3 GPs and 10 mental health doctors (see table 1 for detailed characteristics).

Qualitative findings

Final 72 codes were identified and discussed by the research members who agreed on grouping of the codes into five broad themes (figure 1). The five themes were

Table 1 Characteristics of interviewed primary care workers

No	Sex	Years of working	Education
M1	Male	12	College degree
M2	Female	11	Bachelor degree
M3	Female	17	Bachelor degree
M4	Male	20	College degree
M5	Female	9	Bachelor degree
M6	Female	20	College degree
M7	Female	15	Bachelor degree
M8	Female	22	College degree
M9	Male	30	College degree
M10	Female	6	Master degree
GP1	Female	8	Master degree
GP2	Female	18	Bachelor degree
GP3	Male	3	Master degree

GP, general practitioner; M, mental health doctor.

as follows: most family resources are non-targeted for families living with schizophrenia, publicity of family resource is difficult, burdensome application process of family resources, few available community-based treatment options and stigma affects effective communication between families living with schizophrenia and society. GP stands for the general practitioner who participated in the interview, and M stands for mental health doctor.

Theme 1: most family resources are non-targeted for families living with schizophrenia

At present, the social support for patients with schizophrenia in China is as same for disabled people from other causes, and there are few resources developed specifically for people with schizophrenia. As the GPs stated: ‘Some people never even get married, so they don’t have children to get welfare policies such as tuition reduction’

(GP1). ‘Some policies, such as free admission to the park, are not available to most families. It is impossible for family members to take patients with schizophrenia to the park every day. There should be more effective policies to improve the quality of life of families living with schizophrenia’ (GP3). Furthermore, mental health doctors added that: ‘Most of these families have very low income, the patients are unable to go to work when they are suffering from schizophrenia. The patients are mainly taken care of by brothers, sisters or parents. The caregivers hope that the government could provide more support for patients with schizophrenia than other diseases’ (M2). ‘There should be more family resources developed specifically for families living with schizophrenia to help these patients and their families. The current welfare policy is not applicable to many families’ (M5). ‘Family resources for people with schizophrenia are very necessary. Because of the characteristics of schizophrenia, families living with schizophrenia need more financial support than other chronic diseases, as well as psychological counseling and relevant care support for caregivers’ (M9). Due to the characteristics of schizophrenia, most non-targeted family resources are underused by patients with schizophrenia and their families.

Theme 2: publicity of family resource is limited

One of the GPs indicated that: ‘Even GPs have very little knowledge about family resources and it is difficult for us to explain the policies clearly. For the patient’s family, the way to obtain information about family resources is very narrow’ (GP2). The mental health doctors stated: ‘Different policies are promulgated by various departments. For patients’ families, it is too difficult to obtain information about family resources. Some families living with patients even know little about the policy of free medication’ (M4). ‘There are many trainings every year, but the trainings focus more on the publicity of common chronic diseases, safety and security. I haven’t received any training on family resources. Professionals

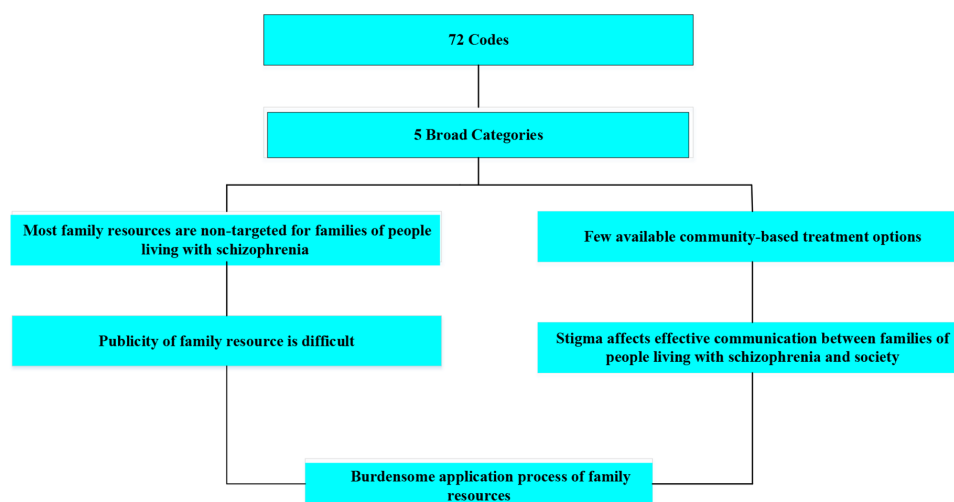


Figure 1 Five categories. Five broad categories grouped from a total of 72 codes generated during analysis.

including me in this CHSC know little about the family resources for schizophrenia' (M6). 'TV and radio often discuss chronic diseases such as high blood pressure and diabetes, but rarely discuss mental illness' (M7). 'Some families living with schizophrenia have no idea about specific welfare policies currently available. I think the best way to effectively use family resources is to provide psychiatric outpatient and general outpatient with a unified brochure about family resources. When a patient is diagnosed with schizophrenia, the doctor can inform the family about available family resources to apply, this is also conducive to enhancing doctor-patient communication and trust' (M8). Primary care workers were even unfamiliar with most family resources and rarely know the process of applying for family resources. And it is not easy for families to obtain information regarding family resource, due to different policies promulgated by numerous departments.

Theme 3: burdensome application process of family resources

It is difficult for families living with schizophrenia to know how to apply for family resources and which department they should go to. 'There is no information network and intercommunication between hospitals and relevant government agencies. This leads to cumbersome application procedures and long waiting time, which greatly affects the utilisation of family resources' (M10). Relevant departments have defined application process. However, interviewees indicated that obstacles such as complicated application process and involvement of private information would all affect the use of resources by families. 'It is not common to apply for family resources for schizophrenia at present. Relevant departments have defined application procedures. This process is too complicated and takes a long time. The amount of subsidy is not large. Therefore, many families are unwilling to apply' (GP1, GP2, M2). 'During the application process, it is necessary to investigate the financial status of families living with schizophrenia and other private information. Some families are not willing to provide' (M1).

Theme 4: limited available community-based treatment options

Currently, medical staff in CHSCs have limited level of medical skills for mental illness. As one of the participants stated: 'Patients don't like to visit outpatient clinics other than psychiatric outpatient clinic because of medical insurance issues, and doctors in other outpatient clinics are unwilling to manage them because of limited mental health skills' (GP2). Furthermore, mental health doctors added that: 'Although schizophrenia has been included in the national public health management package, due to limited mental health skills, some primary care doctors only complete necessary tasks assigned, such as follow-up, but fail to provide real medical assistance such as rehabilitation and care guidance' (M2). 'If possible, it is very necessary for doctors from psychiatric hospital to provide guidance for primary care workers to manage patients in

the community' (M4). 'Patients need to go to a specialist hospital to receive rehabilitation treatment. The rehabilitation phase is long, and part of outpatient rehabilitation treatment is not included in the medical insurance, the pressure is significant' (M9). The connection between CHSCs and the hospitals is weak, and the hospitals seldom provide diagnosis and treatment advice for CHSCs. Patients with schizophrenia are usually recommended to seek care at specialist psychiatric hospitals instead of receiving medical assistance such as rehabilitation and care guidance at the community level.

Theme 5: stigma affects effective communication between families living with schizophrenia and society

Families living with schizophrenia often refuse to communicate with others because of stigma. As the interviewees stated: 'Family members are afraid that others would know their family member has schizophrenia. Some families rarely ask for help from society' (GP3). 'For fear of discrimination from others, families living with schizophrenia are exhausted physically and mentally, they refuse to contact the society' (M3). 'The public health system in China has been working hard on promoting the social perception to reduce or eliminate stigma through mental health publicity and education in hospitals, communities and schools' (M6). 'Patients and their families are defensive and uncooperative with the publicity staffs, which makes it difficult for the staffs to proceed' (M7). 'Stigma is really a common phenomenon, one strategy to eliminate stigma is by social education' (M8). They often refuse to accept help from the society, acting indifferently and defensively. This hinders the social activity of families living with schizophrenia and they cannot obtain information on family resources effectively.

DISCUSSION

Schizophrenia has been generally recognised as a public health issue, it poses numerous challenges in its management and outcome.³² Family resource mediates the impact of schizophrenia on caregiving burdens, as lower family resource is associated with higher level of caregiving burdens.²⁷ Under the Chinese cultural background, family resource is based on a tight network of social relations and is maintained via reciprocal favours.³³ Primary care workers play important roles in managing schizophrenia and coordinating health resources in community. We explored potential barriers for families living with schizophrenia to access family resources from the perspective of primary care workers, which can provide evidence for tailored mental health policies in primary care.

The family resources used by patients with schizophrenia are mainly provided by the Chinese Disabled People's Federation and relevant government institutions. Government institutions have different ways of publicising family resources, and due to constant modifications in the implementation process, it is often difficult to form

detailed operational regulations for family resources.³⁴ Burdensome application procedures and inappropriate quota allocations also impaired the accessibility of family resources. There are numerous governing institutions, which makes it difficult for patients and families to determine which resources to apply for. Simplifying the procedures of applications and acquisition of supports, and increasing targeted resources are important countermeasures to promote the patients' help-seeking behaviour. It is recommended to set up a special agency to provide information about family resources for patients with mental illness.³⁴ A specialised department should be set up in mental health hospitals. When a patient is diagnosed with schizophrenia, the 'Instructions on the Use of Resources for Patients with Schizophrenia' or 'Flow Chart' can be issued to explain the resources and application procedures for their families in detail, so as to improve the efficiency of family resources utilisation.³⁴ Patients with schizophrenia diagnosis certificate should get assistance with the access to family resources provided by the Chinese Disabled Persons' Federation where their household registered.

Schizophrenia is a disease typically begins in early adulthood, between the ages of 15–25.³⁵ Most of patients had impairment in functioning especially in the areas of work, respect for property, recreation/leisure activities, conversational skills, social engagement and instrumental social skills, which play a very important role in daily living. It is proven that social work combined with comprehensive mental rehabilitation training can improve the mental symptoms of patients with schizophrenia and their social function, which shows better effects than simple mental rehabilitation training.³⁶ Therefore, family resources such as tailored vocational training and employment support should be offered to patients, as employment is a key social determinant of health.³⁷ This helps to alleviate increased risk of drifting into or remaining in poverty caused by increased health expenditure, reduced productivity, stigma, and loss of employment and associated earnings based on social drift theory.⁷ It is shown that families living with schizophrenia are more vulnerable to discrimination in China.^{26 34} Patients with schizophrenia and their caregivers have to cope not only with their symptoms but also with prevalent negative societal attitudes causing stigma, which would isolate a family from mutual help and maintaining quality of life.³⁸ The psychiatric stigmatisation and discrimination discourage against families living with schizophrenia might lead to increased physical, mental and financial burdens on family members.^{34 39} It is shown that family-based community rehabilitation including psycho-education significantly decreased family financial burden, increased family employment, and increased the working ability of the patient.⁷ Therefore, antidiscrimination policies and public education on mental health via social media and effective channels should be implemented by the government. There should be psychologists at the community level to help families living with schizophrenia, to encourage, and provide them equal

opportunities as other citizens to participate in social activities.⁴⁰

In low-income and middle-income countries, primary care system should provide essential mental healthcare in cooperation with specialist care system, where the specialist care system alone is unable to cope with the increasing burdens of schizophrenia.⁴¹ Currently, the mental health service of primary care in China focuses more on information management than rehabilitation care. CHSCs are mainly responsible for the supervision of the onset of patients with schizophrenia. It is shown that community-based psychiatric rehabilitation can promote the quality of life of both the patients and their families by achieving social inclusion via the joint efforts of stakeholders.⁴² Therefore, for high-quality management of patients with schizophrenia in community, a multidisciplinary primary care team, consisting of GPs, nurses, psychiatrists, public health professionals, psychotherapists and social workers should be established. Broader coverage of healthcare insurance and more accessible financial protection, such as expanding free medication directories, increasing the proportion of hospitalisation reimbursement, are important ways to support patients to seek medical health services.⁴³ Efforts should be made to increase the use of community-based psychosocial rehabilitation for schizophrenia in China, and strength the existing primary mental healthcare system, allocate more resources for community care and make referral process effective.^{42 44} These may reduce the high costs and overuse of medical resources in hospitals, relieve the burden of health insurance funds and allow for better geographical access.⁴⁵ It is crucial for patients with schizophrenia and their families to achieve family resources via the joint efforts of family members, professionals, service providers and the government.

Important aspects regarding family resources for families living with schizophrenia from the perspective of primary care workers were revealed in this study. As the key staff in the community to reach patients, primary care workers have better understanding than patients and families about the mental health service system, their points could serve as a basis for appropriate and effective family resources coordination in primary care. But it has some limitations. First, the qualitative design lack depth in the analysis—content analysis only offers a surface-level view of the key issues. Second, the study relies on second-hand perspectives from primary care workers rather than families living with schizophrenia. Future research should be carried out to explore the experience of access to family resources for families living with schizophrenia from different views.

CONCLUSIONS

The results of this study may provide reference for the utilisation and coordination of family resources at the primary care level. A training system should be established to improve the capacity of primary care workers to

manage mental illness in community. A family resource assurance mechanism incorporating the coordination of family resources for patients with mental illness should be established in primary care, which can help patients get access to family resources and assist the government to develop new resources.

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Patient consent for publication Not applicable.

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ORCID iD

Xiaoqin Lu <http://orcid.org/0000-0003-3453-9373>

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Objectives: Access to family resources by families of people living with schizophrenia from the perspective of primary care workers in urban Beijing

Meeting Date: September to December 2021, ranged from 30 to 90 minutes in length

Recorder: Two team members

Location: Meeting room

(The interviewer from the research team was experienced in qualitative research and had engaged in community management research of chronic diseases including schizophrenia for ten years. She directed the entire process of the interviews. Before interview, the interviewer introduced the value of the study to the participants. The procedures of the interview were as follows: (1) the interviewees who would like to participate in the study were contacted (2) After informed consent was obtained, the interviewer arranged a face-to-face interview alone with each them for approximately 30 min. (3) The sessions were recorded and transcribed verbatim; the true names of the interviewees were replaced by codes; and the privacy of the patients was well-preserved.)

Interview Guide

1. Do you know about family resources?
2. Can you describe any ways for patients with schizophrenia to apply for family resources?
3. Can you describe any factors affect the use of family resources by patients with schizophrenia and their families?

Prompts: Can you describe these?

4. Are there any ways that would make it easier to use family resources by patients with schizophrenia and their families?

Prompts: Can you describe these?

5. Are there any ways in which you think can be more effective to use family resources for patients with schizophrenia?

6. Is it difficult for you to manage patients with schizophrenia in the community?

Prompts: Why?

How could this be done better?

7. Are there any things that would make it easier to manage patients with schizophrenia in the community?