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Original Article

Using focus groups to design a psychoeducation program for patients with schizophrenia and their family members

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Abstract: The purpose of this project was to determine what factors to be considered in planning a psychoeducation program to better meet the needs of patients with schizophrenia and their family members. Methods: Three focus group sessions were conducted and recorded, transcribed, and analyzed by members of the research team. Results: Patients hoped to grasp the fullest possible knowledge about schizophrenia, whereas the factors influencing the efficacy of the schizophrenia health education curriculum included: discrimination, non-understanding of family members, easy to forget, unreasonable timetable. Health education was mainly in the form of classroom teaching. Conclusions: 1. At present, there are a few psychiatric education courses in China; 2. Patients and their family members are eager to acquire knowledge about the contents of schizophrenia; 3. Misconceptions would hinder the rehabilitation of patients; 4. Worry about being discriminated; 5. There is a different knowledge demand between the patients and their family members.

Keywords: Focus group, schizophrenia, psychoeducation, program

Introduction

Schizophrenia is a severe, lifelong brain disorder that creates difficulty for persons to understand the difference between real and unreal experiences, to think logically, to have culturally appropriate emotional responses, and to behave appropriately in social situations. Not only patients with schizophrenia suffer greatly from this illness, but also their family members. Family psychoeducation has been shown to be an effective intervention for patients with schizophrenia and their family members. Studies have demonstrated the effectiveness of family interventions, including community based psychoeducation, but there is a lack of a standardized family psychoeducation course model in China.

Schizophrenia comprises of a group of psychotic disorders of unknown etiology that typically present with a gradual onset of abnormalities in perception, thought, motion and behavior often during young adulthood [1]. While consciousness is usually maintained and intelligence is intact, there is often significant cognitive impairment. It is the most common and most severe disorder treated in psychiatric clinics. The prognosis is relatively poor compared with the other mental disorders. The natural course of schizophrenia for one-half of patients follows the chronic disease model of acute exacerbations followed by remissions, but for one-fourth of those diagnosed schizophrenia results in ongoing deterioration that requires a lifetime of supervised care [2]. Two worldwide epidemiologic reviews of schizophrenia showed a lifetime prevalence of 5.5 per 1000 persons and a median lifetime morbidity risk of 7.2 per 1000 persons [3, 4]. In mainland of China, 1993 data showed a lifetime prevalence of 6.55 per 1000 persons [5, 6]. More than 7.8 million people in China are diagnosed with schizophrenia. Results of a 1993 survey in Hunan showed a prevalence rate of 9.79 person 1000 persons [7]. Schizophrenia is the most common disease in psychiatric clinics, and is also a severe mental disorder with rela-

tively poor prognosis compared with other mental disorders.

Patients with schizophrenia often suffer terrifying symptoms such as auditory hallucination and persecutory delusions that include the belief that others are reading their minds, controlling their though, or plotting to harm them. These symptoms often leave patients in a state of fear those results in social withdrawal. Additionally, speech and behavior can be so disorganized that patient communication becomes incomprehensible and others are frightened of them. These symptoms can hinder daily life and social functioning to the point of social isolation and inability to complete normal activities of daily living. Available treatments can relieve many symptoms, but most people with schizophrenia continue to suffer daily symptoms of varying degrees throughout their lives.

In China most patients with schizophrenia live with their families. Studies have indicated that due to family ties and expectations, there is a severe burden upon the whole family in caring for a family member diagnosed with schizophrenia. The family must face the daily stressors of unpredictable and bizarre behaviors of their ill relative; external stressors of stigma and social isolation from their own peers; emotional frustration such as guilt and loneliness; family conflicts, and, burnout in the caring process [8-10]. Family psychoeducation can significantly reduce the burden created by these care-giving stressors.

The devastating effects of schizophrenia on family member health and well-being have long been known. Ongoing research projects have explored possible ways to alleviate this family devastation. In the late 1970s [11] family psychoeducation originated as a method of working in partnership with families to help them understand schizophrenia and to develop increasingly sophisticated and beneficial coping skills for handling problems posed by mental illness in their family and skills for supporting the recovery of their loved one.

Many studies have shown markedly higher reductions in relapse and rehospitalization rates among patients whose families received psychoeducation than among those who received standard individual services, with differences ranging from 20 to 50 percent over two years [11, 12]. Family psychoeducation is considered as an effective and inexpensive family intervention for people with schizophrenia.

Research on family management of schizophrenia is in its infancy in China, but several studies have focused on development of education programs and choice of outcome measures. Briefly, all the studies were designed with control groups and used standard diagnostic criteria such as DSM-III-R (American Psychiatric Association, 1987), or the Chinese Classification of Mental Disorders (CCMD-II-R) (Chinese Medical Association, 1995), which divides mental disorders into ten categories. These studies included either individual or group psychoeducation, often combined with antipsychotic drug treatment. There was significant reduction in relapse rates, hospitalization, and the level of psychotic symptoms. Additionally, such programs lead to an enhancement of patients' quality of life and social functioning, with an improvement in family relationships and social environment [13-17].

The studies are often conducted by physicians and psychologists, and few studies have been conducted by nurses in China that identify the effect of patient or family education on people with schizophrenia. China has a large population and the number of psychiatrists is relatively insufficient. It is unrealistic to expect psychiatrists to conduct family psychoeducation in communities because of time constraints and limited resources. Although no uniform appraisal tools for a patient with schizophrenia has been developed in use in China and content of family intervention has not been standardized in these studies. Little consideration of cost of the intervention for patients with schizophrenia has been addressed.

Since there are so many patients with schizophrenia in China, it is impossible for hospitals to adequately accommodate their treatment and educational needs. Because of the rising cost of inpatient hospitalization, inpatient treatment is reserved for the most acute patients. Once stabilization has occurred, the patient is returned to the community for ongoing care, usually for their lifetime as schizophrenia has no known cure. Community care is usually custodial in nature because of scarce resources

Table 1. The main contents interviewed by panel

Theme	Contents
1	Views on current family psychoeducation or psychoeducation.
2	Views on content of the new family psychoeducation program.
3	Views on the design and delivery of the education and course.

with the bulk of responsibility placed on the family.

Because there are not enough mental health service institutions in the community to meet the needs of outpatients with schizophrenia and their family members, there is an urgent need to develop and implement a family psychoeducation program. There is a need to develop a standardized curriculum to provide information to patients and their family members that will assist with symptom management and prevent relapse.

The purpose of this project were to investigate the perceived needs and preferences of patients with schizophrenia and their family members for specific family psychoeducation course content and preferred style of delivery and elicit opinions about what factors need to be considered in planning a family psychoeducation program to better meet the needs of schizophrenia and their families in the community of Changsha, Hunan province, China.

Materials and methods

A focus group method is designed to discover the view of a well-defined population on meeting their specific, self-defined needs [18]. The use of focus group as an assessment and program planning tool for culturally specific education questions and programs has been reported previously [18-20]. The purpose of the focus group interview is to assess the needs of the patients and their family members and obtain practical recommendations for the design and delivery of the future program.

Recruitment of focus group members

Recruitment of patients for the cross-sectional focus group will be conducted by advertisement on the bulletin board of a community of Changsha China. Inclusion criteria are: 1) Adult outpatients 18-60 years old, who live with family members in the community in Changsha; 2) Have been diagnosed with schizophrenia according to CCMD-3 or DSM-IV criteria; 3) Family members are defined as anyone related by blood or affinity whose close relationship with the patients is the equivalent of a family relationship. Family members may be relatives, friends or neighbors who provide main care for the patients in his/her family who are at least 18 years old; 4) Ability to speak and write in Chinese; 5) Representative sociodemographic including age, gender, and education. All participants will be paid $15 for their time. All participants will give informed consent.

This study intends to gather opinions about schizophrenia health education curriculum from patients and their family members. But taking into account the patients and their family members' reluctant to express opinions when they may be present each other, the researchers proposed three group interviews: the first group of patients, the second group of family group and the third group of patients and their family members, i.e. mixed group.

In each focus group 6-10 people with schizophrenia and their families were recruited to attend a two-hour, tape-recorded focus group interview. This is the recommended size.

Design

The semi-structured plan was devised to address key areas, including views on the suitability of the family psychoeducation curriculum and views on both current and future family psychoeducation. The panel interviews the main contents as following **Table 1**.

Before discussing views on the family psychoeducation curriculum participants will be provided with a brief description of the family psychoeducation curriculum and shown a plan of the curriculum and the topics covered. Moderators aim to be as neutral as possible, providing only facts and descriptions of the curriculum. Discussion of 'views on current family psychoeducation' and 'views on the design and delivery of the education and course' will intend to establish whether any particular methods of teaching appeared more or less preferable in terms of encouraging effective learning and engagement.

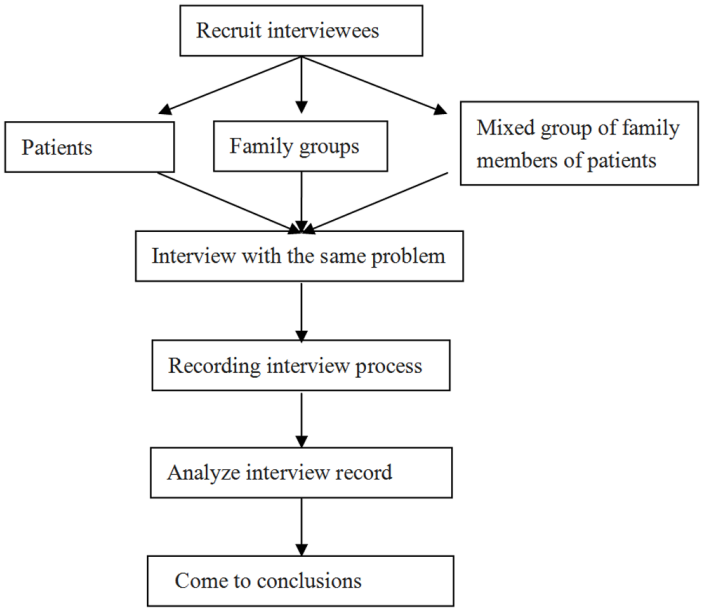

Figure 1. The research flowchart.

Two moderators will be involved in the focus group. They will ensure that no one participant dominates the discussion. The first moderator will lead the discussion, using a semi-structured format developed beforehand. The second moderator will serve as a group co-leader, summarize participant responses and handle logistical issues. No one participant will dominate discussion.

During and immediately after the focus group, fields notes will be taken on key discussion points and observations Confidentiality will be assured and all participants will be encouraged to share their ideas. The research flowchart is **Figure 1**.

Data collection and analysis strategy

Data collection will include basic-demographic information and the transcript form the two-hour focus group. Informed consent will be obtained before data is collected.

Participant demographics will include age, gender, occupation, education, length of time since diagnosis. Data from the audio taped focus group interview will be transcribed verbatim electronically by two assistants. The transcripts will be printed out for analysis.

The text will be read line-by-line and themes identified that best describe the opinions of the group and the range of responses to the research questions. Data will be coded into as many categories as possible to generate a description of the participants as well as categories or themes for analysis [21]. Data will be interpreted and correlated with the demographic data.

The following questions about group dynamics and data will guide the analysis: (1) What are people saying? (2) What are people feeling? (3) What is really important? (4) What are the themes? (5) Were any bits of wisdom said only once but merit noting? (6) Which quotes really give the essence of the conversation? and (7) What ideas will be especially useful to understanding participants' perceptions?

Fidelity of the findings will be addressed in the following ways [22]:

1) Cross-check transcripts to eliminate transcription errors.

2) Monitor for a drift in the definition of codes and for shifts in the meaning of the codes during the process of coding.

3) Coordinate communication among coders by holding regular meetings that will have minutes recorded and by share the analysis with all members of the research team.

4) Cross-check codes developed by different researchers by comparing results through a blinded review.

Results

Population characteristics interviewed by panel

The population characteristics interviewed by panel goes as **Table 2**.

Current understanding of schizophrenia health education

Currently schizophrenic patients and their family members can receive less schizophrenia health education, only a few of the patients received systematic health education curricu-

Table 2. Focus Group Characteristics

Group	Number of people	Ages	Education
Patient	10 (8 males, 2 females)	34-54 years old	High school
Family member	10 (3 males and 7 females)	35-58 years old	Post-primary
Patient and family member	10 (patients: 1 male and 5 females, family members: 2 males and 2 females)	28-75 years old	High school

lum, the curriculum is based on the form of lectures or panel discussions manner. Patients believe that such a course can help them understand schizophrenia, but it also means that as time goes on, not particularly remember the course content. Most people received a brief introduction of the disease when they saw a doctor or stayed in the hospital, with emphasis on the patient's illusion, non-existing, patients should be aware of their illness and adhere to treatment and so on. Obtained schizophrenia information in such a way was limited so that patients and their family members experienced little great help when they were confused in life. Individual held that he or she obtained schizophrenia information through the Internet or reading. But all people want to be able to accept schizophrenia systematic and comprehensive health education curriculum.

Content requirements of proposed schizophrenia health education curriculum

Patients and their family members were very interested in etiology, diagnosis, symptoms and treatment, but worried about too difficult understanding of contents. They didn't understand, so educators should consider the level of knowledge of patients and their family members in preparation for this course, simple and straightforward as possible is needed.

Medicine is the one of key concerns of patients and their family members. They asked "why my child take medication will relapse"; "what kind of effect does smoking has on medication?"; "the medication has a great side effect on me, I do not want to take it anymore"; "I feel very sluggish if I don't take medicine, how to do?"; "medication can cause obesity, how to solve this?" and so on. In a word, the questions are those caused by efficacy of medicine, the factors affecting the efficacy, side effects and how to deal with side effects.

Patients and their family members think this content is very important and too difficult to grasp. Schizophrenia relapse rate is an undoubted fact which the family members worried about, as the family member said, "once the recurrence, we are faced with great disaster", "relapsed patients suffered greatly", "I can not express bitterness in my heart", and recurrence is the greatest burden on the patient's family. How to care for the patient at home and control recurrence is the most important thing for the family members. They are willing to try any measures which help patients control recurrence.

The activities of daily life are considered relatively simple, easy to grasp. However, many patients have said that they have the problem of declining memory, which would interfere with the completion of activities of daily life and medicines taken regularly. So we should provide some enhanced memory ways to help patients better manage their lives.

Patients expressed loneliness, longing with people, wanted to be able to have interpersonal skills. Some family member said the patient wouldn't receipt any harsh words. They hoped courses could offer an effective way to communicate with patients.

The effects of medication and schizophrenia on female menstrual cycle, marriage, birth, offspring health have been repeatedly put forward and they want to know how to reduce the impact to help patients live a normal marriage and family life. Even a member of patient family asked whether or not to help sick daughter marry a male patient with schizophrenia.

The patient said someone ate three owls and cured epilepsy, asking whether schizophrenia had the same remedies. Still, some people said "In the countryside, try a variety of ways superstitious, finally it didn't work, the patient was sent to a mental hospital".

Patients and their family members have expressed demand for social assistance information. Some family members said, "TV news reported that kidney transplantation and cancer patients in earthquakes were rescued. Why

was only a schizophrenic patient not rescued?" The family members worried about how for patients to live after their death, are they homeless?

Factors that may affect the course outcomes

Discrimination: Because of fear of discrimination, one patient said, "I worry about mostly encountering an acquaintance when attending the lectures". Patients and their family members should have considered the courses should be opened in the hospital or specialized mental illness clubs, not in the community.

Non-understanding of family members: The patient thought it is necessary for the family members to receive psychiatric health education with the patients, as a patient said: "..... I know a patient, some time ago, his mother died of leukemia, his father said he felt worse after taking medication and he is not allowed to take medicine, his drugs are thrown, the resultant outcome is his laughing and sick .....". The family members are with the patients for a long time, closely connected, if you cannot grasp schizophrenia-related knowledge and appropriate ways to communicate, which should have direct negative impact on the patient's health.

Easy to forget: Because patients and their family members reflected it was easy for them to forget if no teaching stuff, so that you didn't reach the goal of health education. So we should distribute teaching stuff to the educated when courses begin to to deepen impression. Timetable weekends are the best time so as not to affect some people's work.

Courses form: Most patients and their family members hope educators to teach in the form of lectures, which means that they will not only get the knowledge of schizophrenia, but also can always ask questions, and even ready to accept the teacher's enlighten, or group discussions; Or make health education pamphlets distributed to the patients and their family members in order to read freely; or the curriculum linked to the Internet or made into a television program, patients and their family members can receive education from the TV or internet. All in all, psychiatric health education can be carried out through various channels, but the way we teach courses is accepted by all.

Discussion

Current psychiatric education courses are relatively less in China

At present, China's development of community mental health care is still in its infancy. To patients and their family members can provide specialized health education curriculum is relatively limited. It is very superficial understanding of schizophrenia, even in patients with schizophrenia closely related have limited knowledge, which is an important reason for high rate of relapse of schizophrenia, it turns out giving families and society a heavy burden. Some people believed in superstitions, prescriptions caused condition delays for a part of the patients. Many studies show that mental health education can significantly reduce the recurrence rate of mental illness and readmission rates, which is an effective and economical way of family intervention [23]. We are urgent to develop mental health education programs to actively urge patients and their family members to adopt healthy lifestyle behaviors to reduce recurrence and improve quality of life.

Patients and their family members are eager to acquire knowledge about the contents of schizophrenia

Patients and their family members want the fullest possible understanding of schizophrenia and in the family as much as possible to help patients to face and manage the disease, to reduce recurrence and improve the quality of life. The contents involved are: schizophrenia etiology, symptoms, diagnosis, treatment; drugs; prevention of relapse; management of activities of daily life; interpersonal communication skills; marriage counseling and social aid information.

Drug therapy is the main treatment for schizophrenia, its efficacy determines the extent of the rehabilitation in patients, which should be discussed in details about the interaction between drugs and the effects of food on drug efficacy, reminding patients and their family members to note some of the details in life, so as not to affect drug efficacy or side effects from excessive self-withdrawal, resulting in relapse. Recurrence is the most worried about problem by family members after patients discharged home and no understanding of the

system is often helpless when faced with relapse. But the control recurrence is not a separate content, it relates to the proper treatment of pharmaceutical treatment, rehabilitation training, nutrition, exercise, stress, and integrated content of proper handling of event once relapsed. Whereas the family members often lack an appropriate knowledge and do not know how to deal with the difficulties they come across. In addition, schizophrenia treatment is very expensive, especially hospital treatment costs are often prohibitive for many ordinary families, they would not take the patient to the hospital until the most difficult situation. Family members hope educators to provide with schizophrenia self-management approach. Under the premise of the drug treatment, they can correctly and systematically handle diseases and health-related issues, as far as possible to help patients recover and remain healthy in the family.

The effect on women physiological functions during interviews and concerns of marriage counseling reflect the patients and their family members demanding to live like a normal person, educators provide the knowledge to meet this demand, meanwhile the particularity of the disease should be emphasized, in particular, to provide the most appropriate proposals in fertility and marriage.

Patients and their family members 'thirst for social assistance information reflected this helpless fact that our communities can provide mental health services relatively less, and the resources are relatively less. These courses can only provide these limited social assistance information as much as possible, and real-time updates.

Misconceptions

Patients and their family members have some misconceptions such as "superstition", prescriptions; or dare not criticize the patient in the family, blindly compromise the patients. The family members do not know how to communicate with the patient correctly, otherwise they did not understand correctly the efficacy and side effects of the drug. When encountered side reaction they took self-withdrawal; or that patients often relapsed was because of "not clarifying the truth", so tend to seek psychological treatment. These misconceptions hinder the rehabilitation of patients with schizophrenia. So we should comprehensively consider how to emphasis on the course content in the corresponding sections when design the program.

Fear of being discriminated

The biggest disadvantage of implementation of curriculum is discrimination, patients and their family members do not want others to know themselves or a family member's illness, if encountering an acquaintance in the teaching place, they would rather give up this opportunity for health education; or because of fear of being discriminated, unwilling to attend class, and they hope educators can edit this information into a health booklet issued to them. Health educators should strictly protect patient privacy, it is not allowed to release patient-related information without patients' permission, and provide all possible help to protect the privacy of patient, such as the lectures take place at specialized hospitals or clubs, rather than in the community; time selected is in the rest time, does not affect the normal working hours; lecture information should be issued by clubs or hospital, no published in the community and so on.

The differences of knowledge needs between patients and their family members

Knowledge needs of patients and their family members are the same in many ways, but there are also differences existing such as interpersonal communication skills, and the family members are concerned about the communication with the patient. Their purpose is to better help patients recover through effective communication manner; while the patient is concerned about the communication with outsiders, the purpose is to avoid loneliness and get into social integration. Patients believe that they are very willing to attend such a course, and some families choose to conceal the patient's condition and let patients face this disease, "it is too cruel". Educators also should consider these factors when designing curriculum and should be slightly different focus when dealing with different populations.

As can be seen from the interviews, schizophrenia patients and their family members in Changsha China received less schizophrenia

health education curriculum. Educators should address the needs of patients and their family members to protect privacy of patients and their family members, at same time, to design schizophrenia health education courses with rich content that can really solve its puzzles and problems and to provide educational services for schizophrenia patients and their family members during rehabilitation in Changsha China. Targeted health education can achieve a multiplier effects. Moreover, group interview method is very suitable for health education needs survey. Interviewing can be in-depth understanding the needs of patients and family members for health education form, content, method demand to provide evidence for the next step to carry out health education.

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All authors have no conflicts of interest.

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