

Perceptions of Family Caregivers of Patients with Schizophrenia Towards Antipsychotics Associated Side-Effects in China: A Qualitative Study

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Purpose: To explore perceptions of antipsychotics associated side-effects among family caregivers of patients with schizophrenia.

Patients and Methods: A descriptive qualitative study was applied in a tertiary referral hospital in China. Purposeful sampling of 18 family caregivers of patients with schizophrenia were interviewed about their perceptions towards antipsychotics related side effects.

Results: According to content analysis, three themes emerged from the data: (a) nightmare in the treatment with the categories of sleep disturbances; physical impairment; appearance impairment; (b) opposite attitudes toward side-effect with the categories of being vigilant; do not care; (c) diverse ways of coping side-effects with the categories of asking for help from professionals; self-determined; try any quack's prescription.

Conclusion: The side effects of antipsychotics not only damage the health of patients, but also increase the burden and stress of caregivers. However, caregivers have different attitudes and coping styles about the side effects of antipsychotics. Health professionals should be aware of the influence of individual background and cultural factors on caregivers' attitudes towards drug side effects. Furthermore, health professionals should also provide caregivers with knowledge about drug side effects, coping skills, and appropriate management strategies to promote health outcomes for people with schizophrenia.

Keywords: schizophrenia, family caregivers, antipsychotics, drug side effects, content analysis

Introduction

Schizophrenia (SZ) is a popular disease with the incidence rate of 15.2 per 100,000 persons, affecting 21 million people worldwide.^{1,2} SZ prevails in about 0.63–0.94% of the population (0.81% for the average annual rate) in China, and approximately half of the population with severe mental illness suffer from SZ.^{3,4} The mortality rate of Chinese patients with schizophrenia is higher than that of the general population, and its standardized mortality rate is 4.9, which results in a significant reduction in the average life expectancy and premature death of patients with schizophrenia.⁵ In addition to natural causes such as physical diseases, unnatural causes such as suicide and accidents are also important factors for premature death in patients with schizophrenia.^{5,6} Lots of efforts have been made to treat the disease, and it has been evidenced that antipsychotic drugs can reduce symptoms of psychosis and prevent recurrence, which is the gold standard treatment for SZ.^{7–9} Nevertheless, there are some side effects of antipsychotics such as neutropenia, extrapyramidal symptoms, urinary problems, constipation, sedation, dizziness, drooling, dry mouth, insomnia, hypersomnia, sexual dysfunction and weight gain, risk of metabolic syndrome and cardiovascular disease, menstrual disorders, declining life

expectancy, and cognitive and cerebral damage, etc.^{10–13} which may decrease patients' quality of life. For some patients, they think the side effects of antipsychotic drugs intolerable, resulting in discontinuation of antipsychotic drugs and low treatment adherence, which is detrimental for patients' health.¹⁴ Hence, how the side effects of antipsychotics are considered and handled affects the treatment and prognosis of SZ as well.

For SZ patients, taking antipsychotics is mandatory for their lifelong time, yet they are considered to be incapable of medication management.^{15,16} Patients are taken care of by their family caregivers most of the time,¹⁷ and half of patients regard medication management as the responsibility of their family caregivers.¹⁸ It has been evidenced that the involvement of family caregivers in treatment can contribute to improved compliance of patients with SZ and reduce recurrence.^{19,20} Hence, the side effects of antipsychotics have become a significant concern for patients' caregivers.¹⁵ It is reported that family caregivers are generally distressed about the impact of the side effects of antipsychotics on the physical and social functions of patients,^{15,21} which results in their concern or reluctance to use antipsychotics for their relatives with SZ.²¹ Stomski et al found that family caregivers' knowledge of drugs side effects depended on their relatives' response to the antipsychotics.¹⁵ Little is known about family caregivers' perceptions and attitudes about the side effects of antipsychotic drugs. Existing researches predominantly adopt quantitative approaches and tend to focus on the attitudes and perspectives of patients with SZ on antipsychotic drugs and less attention to family caregiver.²⁰ Considering the key role of family caregivers in the antipsychotic drugs treatment, this study aims to explore the perceptions of family caregivers of SZ towards the side effects of antipsychotic drugs in China, which will contribute to the development of a targeted antipsychotic drugs management plan for family caregivers of patients with SZ.

Materials and Methods

Study Design

A qualitative descriptive study with an individual interview method was used to understand the perceptions and attitudes of family caregivers of patients with SZ towards antipsychotic drugs associated side-effects from December 2020 to July 2021.

Participants and Setting

The study was conducted in the psychiatric department of a tertiary hospital in Yunnan Province, China. Participants were family caregivers of patients with SZ. Purposive sampling methods was administered to provide the heterogeneity of the socio-demographic characteristics of the interviewees.²² Participants were eligible in this study if they met the following inclusion criteria: (1): an adult family member who takes major responsibilities for caring for the person with schizophrenia and has cared for the patient at least 1 year. (2): Willing to accept interviews, have the ability to reflect and express their experiences. (3): Knowing the medication situation of patients with SZ, and their family members only suffering from SZ. The sampling strategy was based on the maximum difference of the participants' educational level, ethnicity, relationship with ill relatives, the course of patients with SZ were also considered, which enabled researchers to obtain diverse perspectives.²²

Data Collection

Before the interview, a self-made questionnaire was used to collect demographic data such as gender, age, ethnicity, educational level, etc. Semi-structured interviews were used to obtain participants' perspectives and attitudes about the side effects of antipsychotic drugs from December 2020 to July 2021.

All interviews were conducted in a quiet and private environment, where participants were free to express their opinions alone. Each interview lasted 35–50 minutes and was recorded. A reflective diary was used to record the interview process in detail and collect non-verbal responses of the interviewees. The interview was conducted by a male nursing graduate student (ZH) who completed the required qualitative research courses, and technical terms were avoided. The interview guidelines were developed based on the pilot interviews, and the following open-ended questions were used to guide the interviews: (1) would you like to share your views on the side effects of antipsychotics? (2) Could you describe the problems caused by the side effects of antipsychotics? (3) Would you like to share with me your experience about how you deal with the side effects of patients after taking antipsychotic drugs? Before the interview, the

interviewer explained the purpose of the research to the potential participants, and the potential participants had time to consider before signing a written informed consent. No one refused to participate or withdrew from the interview. The researcher tried to hide his views during the interview and reviewed his biases on this research before the interview. The researcher had no medical relationship to the participants, and they were assured that their response would not affect the treatment of their relatives. Each interview was conducted only once, after 18 interviews, author noticed data redundancy and information saturation, and ceased interviews. The interviewees were asked to verify the accuracy of the information before the end of the interview. Each recording was transcribed verbatim into Chinese by the interviewer within 24 hours, after the transcript was analyzed, the selected quotes were translated from Chinese to English by two bilingual translators to ensure consistency.

Data Analysis

Data collection was carried out concurrently with data analysis. The data were analyzed using content analysis method.²³ The analysis process included repeated listening to interview recordings and multiple reading of the transcribed materials in order to comprehensively understand the participants' views and experiences of the side effects of antipsychotic drugs. The text was formed into condensed meaning units and encoded, and finally formed into different categories based on similarities. In order to eliminate the risk of bias, two researchers (ZH and MF) with expertise in qualitative data analysis analyzed the interview data independently. The research team thoroughly discussed findings to establish a "consensus", thereby enhancing the validity of the findings. We did not obtain participant feedback on the findings as participants were discharged from the hospital before the analysis was completed.

Ethical Approval

The study complies with the Declaration of Helsinki and was approved by the Ethics Committee of the First Affiliated Hospital of Kunming Medical University. Participants were informed of the purpose and voluntary nature of their participation in the study. They could withdraw from the study at any time without explaining the reason. The confidentiality and anonymity of participants was assured. Permission for interview recording was obtained from each participant. Before the interview, written informed consent from each participant was obtained.

Results

The characteristics of participants are shown in [Table 1](#). Through content analysis of qualitative data, eight categories were identified and grouped into three themes. Theme A: nightmare in the treatment; Theme B: opposite attitudes toward side-effect; Theme C: diverse ways of coping side-effects.

Theme A: Nightmare in the Treatment

Caregivers noted that the side effects of antipsychotic drugs on patients were like nightmare, and which included (1) sleep disturbances; (2) physical impairment; (3) appearance impairment.

Category I: Sleep Disturbances

Some participants stated that the most obvious manifestation after taking antipsychotic drugs was sleep disturbances. Their relatives indulged in sleeping all day, which affected their daily life. Some participants showed that the patient's lethargy made them feel distressed:

After taking medicine, he can sleep from morning to night and from night to dawn, even skipping meals.

Participant 10

I do not know what to do. She had to take medicine to control her condition, but she slept all day after taking the medicine. If she did not take it, her condition would getting worse.

Participant 14

Table I Characteristics of Interview Participants

NO	Gender	Age	Ethnicity	Relationship with Patients	Age of Patients	Educational Level
P1	M	52	Han	Father-son	17	Primary school or below
P2	M	54	Han	Father-son	26	College or above
P3	M	50	Han	Spouse	48	Junior high school
P4	F	44	Han	Mother-son	21	Junior high school
P5	F	42	La Hu	Mother-daughter	13	College or above
P6	M	57	Na Xi	Brother-sister	53	College or above
P7	F	54	Yi	Mother-daughter	30	College or above
P8	F	38	Han	Mother-daughter	13	College or above
P9	M	47	Hui	Father-daughter	18	College or above
P10	F	46	Yi	Mother-son	14	College or above
P11	M	24	Han	Mother-son	45	College or above
P12	M	48	Han	Father-son	16	Junior high school
P13	F	51	Hui	Mother-daughter	25	Primary school or below
P14	F	40	Han	Mother-daughter	18	Primary school or below
P15	F	52	Yi	Mother-daughter	22	College or above
P16	F	65	Han	Mother-daughter	38	High school
P17	M	46	Han	Father-son	22	Junior high school
P18	M	57	Bai	Father-son	31	Junior high school

Category 2: Physical Impairment

Some participants described that their relatives had physical abnormalities after taking antipsychotic drugs. They believed this was caused by side effects, and that long-term use of antipsychotic drugs would damage the physical health of patients:

... She has irregular menstruation after taking the antipsychotic drugs.

Participant 16

... He also developed constipation after taking the medicine.

Participant 12

... The doctor told us that his medicine was harmful to the liver.

Participant 10

Category 3: Appearance Impairment

Some participants felt that the obvious manifestation of the side effects of antipsychotic drugs for patients was the change in appearance, especially obesity. Additionally, some participants felt that patients often drool uncontrollably, which is also a manifestation of drug side effects:

Well, gaining weight was obvious, she was 60 kg before and grew to 70 kg, and at heaviest was over 80 kg.

Participant 16

... Apart from gaining weight, it is obvious that he drools uncontrollably, just like a child.

Participant 17

Theme B: Opposite Attitudes Toward Side-Effect

When talking about caregivers' attitudes about the side effects of antipsychotic drugs, participants reflected the opposite attitudes toward side-effect, which included two categories: (1) being vigilant; (2) do not care.

Category I: Being Vigilant

Some caregivers reported that the side effects of antipsychotic drugs posed a threat to the health of patients with SZ. For the health of their families, they had to be constantly vigilant about it:

As a mother, I always pay attention to the reaction and consequences of my child after taking medicine, which enables me to communicate the effect of antipsychotic drugs with the doctor in detail, and I can better monitor his treatment.

Participant 12

Adverse drug reactions are very important to us. Because our child's liver and kidney functions are poor, if the drug will damage the kidneys and liver, she can not take it.

Participant 18

Category 2: Do Not Care

However, some participants felt that it was normal for the drugs to have side effects, and they were reluctant to pay attention to the side effects of the antipsychotic drugs. They described that the only thing they could do was to give the patient the medication according to the doctor's instructions:

Every medicine has side effects. If I know the side effects of antipsychotic drugs, I would worry about the damage of medication, it makes me anxious, but I could not do anything except give him medicine as prescribed.

Participant 1

Well, in fact, I do not want to know any information about the side effects of these drugs. I am more willing to follow the doctor's instructions, Since we could not understand the information and mechanisms of the side effects ... I can not interfere with the doctor's treatment.

Participant 3

Theme C: Diverse Ways of Coping Side-Effects

Participants recounted their experiences of dealing with the side effects of antipsychotic drugs, including three categories: (1) asking for help from professionals; (2) self-determined; (3) try any quack's prescription.

Category 1: Asking for Help from Professionals

Some participants said that they would ask health professionals for help when they noticed that patients had abnormal reactions after taking antipsychotic drugs. In addition, some participants stated that they would also try to take their ill relatives to consult a Chinese medicine therapist:

She did not have menstruation for three months after taking risperidone, so I quickly took her to the attending doctor.

Participant 6

He has obvious side effects ... so we want to try traditional Chinese medicine.

Participant 17

Category 2: Self-Determined

However, some participants would explain the side effect by themselves and self-determine how to cope with it. They might thought that the side effects of antipsychotic drugs were the result of overdose, and they reduced the patient's dose or stopped using drugs, without consulting a psychiatrist:

He became a little dull after taking antipsychotic drugs. I think it was caused by the excessive dose of the drug, so I gradually reduced the dose of the drug.

Participant 8

I thought too much olanzapine would interfere with sleep, so I did not give it to him.

Participant 11

Category 3: Try Any Quack's Prescription

A few participants suggested that other patients were normal after taking the antipsychotics, but not for their relatives. They thought it was a catastrophe that was beyond the reach of science, they had to ask geomancer for help:

There is nothing I can do, other patients are normal after taking the medication except her ... After we were discharged from the hospital, her uncle asked us to visit a geomancer who was able to separate my deceased husband from my daughter. He felt that my daughter had side effects ... It might be that her dead father got entangled with her.

Participant 15

Discussion

This study explored family caregivers' perceptions about the side effect of antipsychotic drugs taken by the patients. We found that family caregivers considered the side effect of antipsychotics as the nightmare, such as sleep disturbances, obesity, drooling, irregular menstruation, and impaired liver function and constipation, which were reported in previous studies.^{9,15,16,21,24} Most Chinese have high expectations for their children, and it is their duty as parents to raise a competitive child and bring honor to the family.¹² However, the side effects of antipsychotic drugs impair the physical and social functioning of patients with SZ, as well as their learning and employment.¹⁵ This ruined their hopes for the recovery of their patients with SZ and the future of their families. For caregivers, limited knowledge and heavy care burdens prevent them from effectively identifying and responding to drug side effects.^{24,25} Hence, Health professionals should evaluate the patient's medical history and medication interactions before recommending medication regimens, and family caregivers should be provided with information about side effects of antipsychotics and coping skills. Health professionals also can mitigate the effects of drug side effects on patients by building a strong support system and implementing health strategies, such as dietary modifications, stress relief, and exercise regimes.²⁴

Our study showed that family caregivers had two opposite attitudes towards the side effects of antipsychotic drugs. Some family caregivers felt vigilant about the side effects of antipsychotic drugs. There is a widely popular Chinese proverb "Every medicine has its side effect". When people were sick, they believed that medicine would not only cure the disease, but also damage their health. Therefore, the family caregivers of patients with SZ take it for granted that the drug must have side effects, and which should be taken seriously. In traditional collectivist core values, the Chinese people are also considered obliged to take care of family members.²⁶ Family caregivers take on caring responsibilities proactively to avoid social denunciation from other culturally inclined people. Tang et al reported that family caregivers with stronger cultural values tended to adopt a more positive attitude toward care-giving,²⁷ which lead to the fact that family caregivers are more alert to the damage of patients caused by side effects of drugs. Nevertheless, some participants were indifferent to the side effects of antipsychotic drugs, preferring to administer the medication as prescribed. This was similar to the results of Morrison et al²¹. Chinese people highly respect health professionals, and they often play a subordinate role in doctor-patient contact.²⁸⁻³⁰ This might lead them to believe that it is useless to focus on the side effects of antipsychotic drugs, since health professionals are able to treat the health problems of their ill relatives. Furthermore, caregivers tend to accept fatalism when they find that the side effects of drugs are beyond their control and they cannot change the outcome.³¹ They insist that drug side effects are predestined in advance for all time and that they doing anything is futile. Health professionals should be aware of these phenomena, know how to handle this problem, and everything is under the control of the professionals.

Our research also found that some family caregivers turned to health professionals when their ill relatives experienced drug side effects, and they would consult with a Chinese medicine (TCM) therapist, which might be due to the importance of TCM in traditional Chinese culture. Unlike western biomedicine, Chinese medicine was rooted in Taoism and has been serving the public for thousands of years.^{28,32} Modern Chinese medicine is an attempt to merge traditional medicine and modern medicine, and Chinese people continue to retain strong traditional beliefs. Therefore, when there are side effects from taking antipsychotic drugs, Chinese people would turn to Chinese medicine therapy.²⁸ In our analysis, some participants adjusted or discontinued medication for patients without consulting a psychiatrist, which has also been reported in previous studies.^{20,21} This may be because caregivers are concerned about the side effects of antipsychotic drugs on patients.³³ They failed to seek help from health professionals, which might be linked to social discrimination and stigma in patients with SZ.³³⁻³⁶ Asian cultures generally value conforming to norms, so anything seen as outside the norm, including mental illness, was viewed with stigma.²⁰ Chinese people emphasize the importance of saving face and maintaining a good reputation for their families, which can lead them to withhold family members' illnesses and even give up seeking health professional services in order to avoid social stigma.^{37,38} In addition,

inadequate information given by doctors and nurses, the lack of knowledge about the available treatment, unaffordable high treatment costs, and poor transportation are also reasons why family caregivers are reluctant to seek professional help from a psychiatrist when side effect occurs.^{39,40}

Our research also revealed that some participants sought help from a geomancer when their relatives experienced side effects from antipsychotic drugs, which had been reported before.^{20,41} “Rationalization” is a common defense mechanism, and when other patients are normal, but the caregiver’s relatives have side effects after taking the drug, from the caregiver’s point of view, finding a geomancer is a reasonable solution.⁴² It has been shown that 7.9% of Chinese caregivers insisted that the abnormality of mentally illness patients was caused by ghosts and gods.⁴³ The central tenets of Taoism holds that there is a middle world between the two ideal worlds, which is the realm of demons and ghosts. These ghosts roam the real world and cause abnormalities in people, and Taoists (geomancers) have a knack for capturing, taming, and annihilating them.^{32,43} Therefore, when treatment fails to meet the expectations of family caregivers, they turn to traditional healers,¹⁴ which is also their available means of denying mental illness and avoiding social stigma.²⁰

Strengths and Limitations

This study explores family caregivers’ perceptions and coping of antipsychotic drugs’ side effects in a Chinese context, emphasizing that culture is a key factor in influencing attitudes and perceptions of the side effects of antipsychotic drugs, which brings new directions for health professionals to develop medication management programs for family caregivers of patients with SZ. The limitation of this study was that the family caregivers were from Yunnan Province only, which reduces the generalizability. Participants’ cultural differences and various religious beliefs may lead to different outcomes. In addition, the fact that most family caregivers are parents of patients with SZ allows the perspectives of other caregivers to be overlooked. To protect the privacy of their children, parents are reluctant to attend focus groups to further explore their perceptions about the disease. Future studies could be conducted with different data collection methods among different caregivers to enrich the findings.

Conclusion

Our findings elucidate the perceptions and experiences of antipsychotic drugs side effects among family caregivers of patients with schizophrenia, which can inform health professionals on how to develop effective medication management plans for family caregivers. Our study highlights that the side effects of antipsychotic drugs increase the burden and stress on caregivers, and it is essential to provide family caregivers with knowledge and coping skills related to the side effects of drugs. In addition, health professionals should consider the influence of individual background and cultural factors on family caregivers’ attitudes toward drug side effects, and help family caregivers understand that antipsychotic drug side effects are common and raise their awareness of drug side effects. At the same time, health professionals should inform family caregivers of appropriate management strategies for drug side effects to promote health outcomes for patients with schizophrenia.

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Author Contributions

All authors made significant contributions to the work of the report, whether in conception, study design, execution, data acquisition, analysis, and interpretation, or in all of these areas; participated in drafting, revision, or critical review of the article; and finally Approve the version to be published; have agreed on the journal to which the article has been submitted; and agree to take responsibility for all aspects of the work.

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