



Exploring Stigma Experiences Using Group Therapy Amongst People Living with Schizophrenia in a Psychiatric Day Care Center

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Abstract

Aim

To explore the lived experiences of stigma among people with schizophrenia in a psychiatric day care center.

Background

Stigmatization can create negative feelings in people with schizophrenia and exacerbate the symptoms of their illness. People in society of Taiwan try to understand the disease of schizophrenia; however, the past perspectives (e.g. crazy, violence, etc.) to people with schizophrenia still exist in people's mind. The management of stigma among people with schizophrenia is an important issue worldwide.

Design

A descriptive qualitative approach was used to study the stigma experiences among patients with schizophrenia using group therapy and two pre-post personal face-to-face interviews at a psychiatric day care center in Taiwan.

Methods

Nine focus groups with six patients were facilitated by a psychiatric nurse practitioner and psychologist. Each group meeting lasted approximately 90 minutes. The research data were collected through participant notes, observation, and twelve informal conversational interviews. The collected data were analyzed using content analysis.

Results

Three core themes were derived from the analysis of the data: 1) stigma due to illness; 2) anti-stigma coping methods, and 3) strategies for fighting stigma.

Conclusion

According to the findings, we understood the feelings and experiences of stigma among people with schizophrenia through the nine focus groups and pre-post interviews. The findings could be utilized by mental health nursing staff when caring for patients with schizophrenia in a clinical setting, and by health educators when teaching nursing students, in order to assist with changing perspectives about people with schizophrenia.

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Keywords

Stigma Experiences, Schizophrenia, Psychiatric Day Care Center, Mental health, Nursing staff

Background

Schizophrenia is a chronic brain disorder. The primary treatment for schizophrenia is usually medication and psychotherapy. Both treatments can improve psychotic symptoms; however, most patients still suffer from symptoms that accompany them throughout their life [1].

The World Health Organization [2] estimated that schizophrenia was the fifth leading worldwide cause of the global disease burden. Over 80% of patients with schizophrenia are affected by stigma and discrimination in Taiwan [3].

Social stigma could make these patients hide their illness, including isolating themselves from society to avoid being labelled [4]. This behavior made these patients keep away from social resources, but also rejected formal medical treatments, which further influenced on the perceptions and judgments of Schizophrenia, resulting in social stigma. Social stigma should not be underestimated, as it could create negative feelings and distress in patients, which could increase over time [5].

The term “stigma” originated from the Greek word “stizein”, meaning the symbol of a tattoo. In ancient Greece, tattoos were used on slaves to identify them as inferior goods by nobles, and in order to distinguish between slaves and normal persons [6]. In 1963, Goffman extended the definition of stigma to include a symbol on the body indicated an abnormal or bad state, or incompatible social norms and cultural expectations. Today, stigma is widely applied to dishonourable events and in relation to mental illness [7], and is divided into public stigma, self-stigma, and structural stigma [8,9].

Culture, beliefs, and people’s perceptions affect the lived experiences of stigma among people with schizophrenia. Asians believe that schizophrenia is a type of supernatural power; a punishment from God [7], and the result of bad deeds from a previous generation or causal explanations [10]. In addition, Asian cultures exhibit a strong need for certain norms, emotional self-control, collectivism, and filial piety [11]. Therefore, when someone is considered to be in violation of these norms, has achieved no academic success, or has no filial piety towards their parents; they are devalued, leading to stigmatization [12].

In Taiwan, in order to increase acceptance of patients with schizophrenia, the Chinese name of schizophrenia has changed from “spiritual break” to “dysfunction of thought and perception” since 2014. However, patients with schizophrenia still face fear and misconceptions from the general public. Stigmatization can create negative feelings in people with schizophrenia and exacerbate the symptoms of their illness [13]. People Taiwanese society has attempted to understand the disease of schizophrenia; however, the past perceptions (e.g., supernatural power; a punishment from God) of people with schizophrenia still exist in people’s minds. An understanding the experiences of stigma surrounding people with schizophrenia is an important issue worldwide.

Research Methods

■ Aim

The aim of this study was to understand the stigma experiences by using group therapy amongst people living with schizophrenia in a psychiatric day care center.

■ Design

A descriptive qualitative study was selected for the present study, as the purpose of the study was to understand the lived experiences of stigma among people with schizophrenia in a psychiatric day care center.

■ Study setting and participants

One psychiatric day care center was used in this study. The day care center was located in the large Memorial hospital in Taiwan, and included thirteen patient’s total. Among them, only six patients who were diagnosed by psychiatric doctors with schizophrenia were stable and willing to participate in this study; others were diagnosed with mood disorders. Although the number of the participants was only six, Krueger and Casey [14] indicated that six to eight participants in group therapy could achieve the best benefits.

■ Data collection

The research data were collected through participants’ observation and discussion from group therapy (nine times), and two pre-post personal face-to-face interviews that were held

over the period of 1st August 2015- 1st December 2015 and 1st February 2016- 1st December 2016. All participants in this study were all diagnosed by psychiatrists as suffering from schizophrenia according to the DSM-V, were aged 20 years or older, had capacity to consent, could understand Mandarin and Taiwanese, and agreed to participate in the study. This research was conducted in the day care by the researcher (psychiatric nurse practitioner at the day care) and a psychologist who worked at the psychiatric day care for more than five years by using group-based therapy for people with schizophrenia. The nine-time group therapy was facilitated following the findings from the Yanos, *et al.* [15] study (Table 1). Each group meeting lasted approximately 90 minutes. The group members named the group sessions “Erase the Past, Embrace the Future.” The interviews were taken before and after the group therapy by the same researcher. Each interview took from 60 until 90 minutes to understand their experiences of stigma.

The content of the nine-session group therapy is listed in Table 1.

Ethical Considerations

The research was approved and the participants were guaranteed human subject protection by the Hospital Institutional Review Board (103-3033C). In addition, the researcher explained the aim and methods of data collection methods of the study to the participants. The participants were also informed of their right to withdraw from the study at any time. The participants signed a consent form to indicate their willingness to participate in the study.

Data Analysis

All data analyses followed the method developed by Greatrex-White [16] and van Manen [17]. During the transcript analysis process, the researcher listened to the interview tapes several times, and made notes and informal observations were taken for future reference in the process of analysis. The benefits of having the researcher transcribe her own interviews was that it allowed

her to become more involved in the research process by being able to reflect on the actual transcript content as well as the actual interview itself [18].

Prior to the commencement of the analysis process all interview data were transcribed in Chinese the language in which the interviews were conducted and subsequently translated into English by the researcher, who was able to converse in both languages. The transcription process involved the researcher listening to the interview tapes several times, and making notes (for future reference during the process of analysis) about the participants’ tone of voice when describing their experiences, pauses in conversation, and emphasis on certain points that were important to them.

After completing translation process and prior to commencing the analysis process, all interview transcripts were given to a licensed professional Chinese-English translator (Taiwanese) to review the English translation of the interviews and to back-translate the transcripts from English to Chinese to determine the accuracy of the original Chinese interview transcripts. The process of analysis commenced once the accuracy of the translation process were determined.

Data analysis was undertaken using three core processes of hermeneutic approach: Dwelling with the text in search of the meaning of the phenomenon under study; interpreting the words, phrases, sentences of the interview texts. Synthesizing the ideas into a formal presentation of research results [16,19].

Results

Six patients (Table 2) completed this study. Details about the participants in this group are provided in Table 2.

During the group discussions, participants not only listened, but also shared their own experiences of the stigma caused by their illness during their lives. The data were organized into three themes: 1) stigma due to illness; 2) anti-stigma coping methods, and 3) strategies for fighting stigma.

Table 1: Content of nine-session group therapy.

1. Introduction	2. Identify myths about stigma	3~4. Two Sharing lived experiences of stigma sessions
5~6. Two Cognitive behavior therapy classes	7. Psycho-education of mental health	8. Psychodrama
9. Review and evaluation		

Table 2: Demographic data.

Participant	Age	Sex	Education	Living status	Onset age	Religion	Onset
A	51	Male	Senior	Alone	19	Taoism	School stress
B	39	Male	Senior	Parents	24	Buddhism	School stress
C	29	Female	Senior	Dad & brother	15	No	Social stress
D	57	Female	University	Sister	19	No	School stress
E	54	Male	Senior	Parents	28	No	Job stress
F	24	Female	Senior	Parents	17	Buddhism	Family stress

■ **Theme one: Stigma due to illness (n=6)**

People with schizophrenia attempt to fight the symptoms of their mental disease and endure the peculiar looks from their family, relatives, and friends. However, their families, relatives, and friends still treat them differently due to public stigma.

After the participants were diagnosed with the disease, their family members took on the responsibility of caring for them; however, they had limited knowledge of the disease and its treatments. What the participants needed during their illness was company and support from their families. However, their families generally made things difficult for them and isolated them from others. As participant F [female, 24 years] said:

Family should encourage us to fight the disease... However, my family [is] concerned about other people's safety when the drug's side effects occur. They attempt to separate me from others. I [am] just like a bird that would like to escape from [its] cage. However, there is a cage waiting for me back home. Then, sometimes I feel heart-broken when my family closes my door. ...After that I still need to go back to the nest. Although I know I need to control my mood, it is difficult for me. So, sometimes I just cry in [my] bedroom, or listen to music in my room. I also draw fish and wished I could live better than before.

The families of these participants sometimes lacked knowledge and did not know how to interact with these participants. Their behaviors and attitudes generally made the patients unhappy and they experienced stigma. Participant C [female, 29 years] claimed:

My family is not willing to interact with me, they refuse me. They all said that I'm abnormal because I have this kind of disease. They think my thoughts and my perspectives are different from others. It seems that they think that I'm

stupid; they don't want to talk to me. It doesn't look like we are a family because we don't take care of each other... My family always says I can't do things well. A while ago, I had some mental problems. My family wanted to take me to the police station, and put me into jail, and not to let me out. I felt [I was] not being respected."

Participant D [female, 57 years] also complained:

My mother and my younger sister asked me not to talk to guests, or to stay off the first floor of our home, just stay on the second floor. They said [it was] because I would talk [about] a lot of things and those things were nonsense.

In addition, in local Chinese culture, the media (e.g., news or newspapers) exaggerates the truth in order to attract the readers' attention by using provocative headlines. This creates a misconception in the population about mental illness. Taiwan's social media is overreaction and unaccepting of people with schizophrenia. Their situations are more difficult due to stigmatization from the media and misconceptions and labels from their family and society. People with mental illness in Taiwan are often viewed as "mad men". Participant E [male, 54 years] explained:

When I was little there were some people who looked like "mad men" in the village. At that time, we didn't know they were sick, so we called them "mad men" as well. Some people got sick due to broken relationships; they usually had long disheveled hair and their faces were different. We saw them and felt scared. Then, I found myself as one of them, and was labelled a "mad man".

When society views people with mental illness negatively, patients suffer from discrimination and unfair treatment, especially in interpersonal relationships. Stigma increases the distance between patients and the world; thus, patients generally hide their condition to avoid becoming

a victim of stigma. Participant C [female, 29 years] stated:

It was difficult for me to get along with others, before I got sick. I still feel confused [about] why I can't make friends, even [though] I don't hurt anyone. In senior high school, my classmate and I went to the counselling centre. I told my teacher I had schizophrenia. From then on, I felt myself be neglected by my classmates because I told everything to the one who went to counselling center with me. After that, my relationship with my classmates was ruined because of my illness. They looked down on me and treated me differently than before. Additionally, I went to Min Syong Church, and I told them that I was having therapy at the Department of Psychiatry during our conversation. Since that time, when people hear about me, they stop talking to me. Now my classmates don't accept me, and even my family does not as well."

Participant A [male, 51years] stated,

I invested in a company with my friend. At that time I wasn't taking medicine and they didn't know about my condition. They thought I did a good job, so we became partners. Once they knew about my disease and my symptoms worsened, my boss said that his company was shutting down and asked me to leave. Later, I applied for a new job working in a bread shop. When I had my interview, the lady asked me to read the contract. On page two [of the contract], it said that people with mental illness would not be hired. It is such a pitiful world for people with mental illness, especially people like me.

■ Theme Two: Anti-stigma coping methods (N=6)

Several anti-stigma coping methods were used by the participants. The stigma and illness hereditary affected patients' attitudes towards their marriage and how they viewed themselves. Participant E [male, 54 years] stated "I envy the people who married before I have not been sick, not only the hereditary but also the medications impaired my sexual function, it is impossible to have children, and then it does not matter that I am not married". The participants expressed their thoughts by drawing a picture because they could not express their thoughts and feelings by talking. They used drawing as a way to communicate their innermost feelings [20]. Participant C [female, 29 years] stated:

Due to the impact of stigma, I blame everyone for everything. I'm afraid of expressing my

feelings. And then, I found myself like living in the past and sometimes found that people were like demons. I can't lie to myself that I live happily, so I just draw the tree to represent [that] I'm always lonely, even now. No one makes friends with me. At that time, my personality was a little bit unsociable. I didn't like to talk or chat with anyone. So, I always got a bunch of peculiar looks from them. My performance in school was better than others; however, I didn't have friends. During my school days, I felt more alone and helpless. Now I can draw to express my loneliness.

Participant A [male, 51years] also painted to copy with stigma:

The painting shows my feeling about psychiatry patients. The implication is that I am hiding in the dark corner, sometimes sweating, cold sweating, and my heart tends to be more to the dark side. When painting the tree, it means the light side; facing others is the light side. It stands in strong contrast to the dark side. I would like to express with strong contrast that when psychotics stay in a room alone, they become panicked and feel scared.

As most Asian religious cultures pray to the deities to bless individual's health, family members also consider becoming ill to be Stigma (a punishment from God). Family members try many alternative therapies for recovery. Participant F [female, 24 years] explained as follows:

My family believed that I was possessed by a spirit because they thought I was weird. Actually no one was talking to me at that time, but I still had conversations with it (auditory hallucination). When I got the illness, I went to exercise two or three times per week. The reason was to exercise to relieve the stress [of stigma] for spirit possession. My father stewed a pot of soup for me, and my grandmother collected some herbs, even [though] she didn't know what it was. My mother bought ham to mix with medicinal liquor to help me relax my muscles. However, it didn't work. I still felt uncomfortable and uncontrollable and I wasn't possessed by a spirit.

Writing in a diary is also another copy method to recover from feelings of being stigmatized.

Participant D [female, 57 years] also said:

There's a distance between some people, such as my family, other neighbors and the public, and me. If I still take the medicine, I won't hurt

anyone, and neither will others. My family, other neighbors and the public should not be stigmatizing us. When I have bad feelings, I usually write them in it (the diary). Then, I feel better.

Many participants find that as long as they take medicine and receive regular treatment, their illness does not worsen.

Participant C [female, 29 years] described:

My brain isn't smart, and I still have the treatment in the hospital. Since I can't work now, I must have the medical treatment. I won't think of anything, only writing it in my diary. That's what I really need to directly tell to others, such as my friends and my family. People with schizophrenia who take medicine regularly will be like other normal people. My friends and my family should not be scared of me.

■ Theme three: Strategies for Fighting Stigma (n=6)

Most participants' illness could improve if their families supported them and some participants used other coping strategies. All of the participants were undergoing rehabilitation at a psychiatric day care center. A regular life and course schedule gradually helped these participants establish their main life goals. Participant E [male, 54 years] described:

I'm very appreciative of the teachers and health care workers here that hold courses for us every day. It seems like we have jobs like normal people. Thanks for accompanying [me] during the courses.

Participant A [male, 51 years] stated:

I think stigma and I are peas and carrot (meaning stigma and the schizophrenia which the participant has gone well together). I will also rely on teachers to understand it. Through teachers and doctors' therapy, we will adapt to it. We will think too much because of this disease. We need to cooperate with doctors and nurses. This is the stable way to control the illness and make people accept us. It would be troublesome if the condition was bad.

Participant F [female, 24 years] also indicated:

Besides regular life, I could learn something here and take care of myself. At least it is not a degenerative disease. However, it's so difficult for us to think about facing a crowd. We should

try it to take the first step, and then we'll know whether we can do it or not. Instead of complaining [about] everything, we have to manage our life."

The issue of the stigma surrounding mental illnesses has starting discussion worldwide. The efforts of patients, governments, and media assist in normalizing these illnesses and help the patients find their strategies for fighting stigma. Participant E [male, 54 years] said:

[I have been] taking medicine for 25 years. No matter [whether] our society accepts it or not, we all need to take medicine, or it is bad for our illness. This is an illness; we can't control physical illness, such as high blood pressure and diabetes.

As knowledge about mental illnesses increases, understanding the stigma related to mental illness allows patients with mental illness to improve their lives. Participants were willing to face to their illness. As a result, their relationship with others changed.

Participant B [male, 39 years] explained:

I also thought it was stigmatization in my past. After I participated in the Phoenix Competition (a national sports congress for mental disorders in Taiwan), I didn't think that anymore. Their illness is more serious than mine, but I saw them still being focused on training and [being] highly proactive. I admired them because they all got the prize.

Participant C [female, 29 years] further indicated:

Recently, I joined a folk dance. I felt scared at first because I was afraid they would isolate me like my classmates [had] before. Since I participated, I felt happy and confident. It made me feel better able to sleep at night. They all asked me whether I have a job now. I said I stay at the hospital as an inpatient. They didn't push me out of the group because of that. If I had a question I would ask them. It made me feel [that] facing people is not as hard as I thought. We all need to try.

Participant A [male, 51 years]:

I like having the class here. I saw that the patients here can also make coffee at the café. Patients can do things and among them, I have even known as the one with a mental illness. I have faced a lot of difficulties and trouble. I don't want to be failed again because of schizophrenia. Schizophrenia is a kind of disease that's not as terrible as the public feels about it. We feel that the public thinks the person with mental illness

has been stigmatized, [that] this kind of thing due to a lack of understanding of the disease....

Also, the participants felt group therapy gave them support and made them have power to face their future. As stated by Participant A [male, 51years]:

Because our condition is the same, if we talk about it with other patients' encouragement, we will not have fear of this disease. Besides, our fear of the disease is more likely reduced and we won't even stop taking the medicine for no reason. After speaking out for our illness condition for many times, we feel better than before.

Participant F [female, 24 years] also shared:

After sharing, I think I will know others a little bit more. Because of that, I know some people may feel uncomfortable. Actually, I thought they won't have the same feeling like me at first. However, group sharing and group therapy did work for me. I hope that can continue anyway.

Discussion

The data interpretation process resulted in three themes: 1) stigma due to illness; 2) anti-stigma coping methods, and 3) strategies for fighting stigma.

As a result of stigma due to illness, patients perceived a high level of stress that exacerbated their disease; hence, they did not want to seek therapy. They gradually experienced poor occupational performance, felt devalued by others, and were fearful due to regression. This was a new finding. Stigma has been widely discussed in recent years, and "being labeled" in this study was consistent with Chen [21] who concluded that stigma disturbs the life adaptation of patients with schizophrenia. Patients conceal their disease to avoid being labelled, and media portrayals reinforce patients' perceptions that they will not be accepted. However, there was less focus on the stigma experiences of patients with schizophrenia in a previous German study where Schulze and Angermeyer [22] conducted a focus group to explore stigma from the subjective perspective of people with schizophrenia, and most patients believed that the diagnosis of schizophrenia resulted in reduced social contact. The public image of schizophrenia is that sufferers are crazy, untrustworthy, and irresponsible, leading to feelings of discrimination during contact with mental health professionals [23]. This result was

inconsistent with the finding of the current study. The reason could be that the participants did not express these feelings perhaps because the leader of the group was a ward staff member. Besides, our group conducted the participants who were treated in day care center and attended many rehabilitation programs for a while, and did not just only take hospital medicine alone. The result could be different from the patients who only took medicine. This might require further research to compare between different areas of patients in the communities. Self-stigmatization gave participants low self-esteem. They were afraid to marry and could not achieve role identity. This result did lend support to Karid study, where almost all participants reported an experience of self-stigma.

For anti-stigma coping methods, most patients wrote in a diary, painted, and took exercise, as their anti-stigma coping methods. No studies could support this result; however, many studies have shown that art can be used to motivate people with mental problems to express their feelings, thoughts, and emotions [19,24]. Besides this, family was the main social support and care helped patients to adhere to treatment in a day care [21]. However, family members became caregivers who usually avoided seeking psychiatric help and tried alternative therapies to cure the disease; the families' reactions generally influenced the patients' process of recovery. According to the patients' descriptions, family support and care influenced the patients' willingness to accept treatment and look for a doctor. This finding was consistent with Wang [25], who concluded that family was mainly medically responsible for patients' treatment. Their emotions and sadness were affected by the burden of caring for the patients, which also lead to stigmatization. The participants in the current study expressed their desires for and positive impact of their family's support and care. As we found, the participants' family support more, their willing of anti-stigma higher [21]. However, not every patient had family support. Further research should include more participants without family support or could explore these family's experiences to understand which factors influence family support to these patients.

Regarding to strategies for fighting stigma due to illness, when patients achieved stability in their condition, hopelessness and low self-esteem were neutralized through the day care rehabilitation. Liu [26] also mentioned that the self-concept

of mental illness could be restored and patients could solve their problems through a therapeutic course and discussions with medical staff. In other words, rehabilitation enhances adaptation, and once the patients enhance adaptation, they would have resilience to find anti-stigma coping methods. In addition, the results of the current study indicate that patients perceived less discriminatory language, fought stigma through the positive energy of other patients, and reconstructed interpersonal relationships. Liu [26] outlined that medical assistance, insight enhancement, good adherence to treatment, and encouragement from other residents could reduce social stigma. Moreover, Liu [26] also admitted that not all patients would choose these strategies, as all patients were different.

The results presented here will not only assist medical staff in understanding a patient's treatment and experience of stigma, but also assisted participants in understanding other people's ideas, encouraging one another, expressing their own problems, and sharing coping methods. Stigma reduction was visible in the participants.

Limitation

Three limitations involved in the conduct of this study are as follows:

First, the small number of participants excludes generalisation of findings (although, this is not the intent of a qualitative study). Second, conducting a study in two languages has the potential to create difficulties in accuracy of translation and ensuring the essential meaning of what is shared by participants is not lost or distorted. Difficulties were encountered by the researcher as a result of having to translate participant interviews. However, every means was taken to ensure that the integrity of the information gathering process and the process of analysis was not compromised. Finally, because the researcher as also the leader of the group was a ward nursing practitioner there, the participants knew each other for more than five years, they might hide their negative feelings or emotions and try to give the researcher positive feedbacks and support her.

Conclusion

The focus groups not only determined the domains in which stigmatization was experienced but also helped to reduce the fear of stigma. However, this method is limited in terms of the generalizability of the results, as the participants were recruited from a psychiatric day care center of a southern teaching hospital, which may not be representative of other populations.

The findings could be utilized in the following ways: 1) to assist nursing staff caring for patients with schizophrenia in understanding the coping experiences of patients with schizophrenia, 2) to assist psychiatry staff in the ward or the nursing educator when teaching in schools, and 3) to increase awareness about mental illness in society and the media to reduce negative perceptions of patients with schizophrenia and to promote empathy, thereby reducing myths about patients with schizophrenia.

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Conflict of interest

There are no conflicts of interest for all authors in this study.

Contributions

Study design: YK, RH; data collection and analysis: YK, RH, and manuscript preparation: YK

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