

Family Carers' Experiences in Striving for Medical Care and Finding Their Solutions for Family Members with Mental Illnesses

Yu-Yu Wang, Shih-Hua Hsieh, Ru-Shian Hsieh

Abstract—Wishes and choices being respected, and the right to be supported rather than coerced, have been internationally recognized as the human rights of persons with mental illness. In Taiwan, 'coerced hospitalization' has become difficult since the revision of the mental health legislation in 2007. Despite trend towards human rights, the real problem families face when their family members are in mental health crisis is the lack of alternative services. This study aims to explore: 1) When is hospitalization seen as the only solution by family members? 2) What are the barriers for arranging hospitalization, and how are they managed? 3) What have family carers learned, in their experiences of caring for their family members with mental illness? To answer these questions, qualitative approach was adopted, and focus group interviews were taken to collect data. This study includes 24 family carers. The main findings of this research include: First, hospital is the last resort for carers in helplessness. Family carers tend to do everything they could to provide care at home for their family members with mental illness. Carers seek hospitalization only when a patient's behavior is too violent, weird, and/or abnormal, and beyond their ability to manage. Hospitalization, nevertheless, is never an easy choice. Obstacles emanate from the attitudes of the medical doctors, the restricted areas of ambulance service, and insufficient information from the carers' part. On the other hand, with some professionals' proactive assistance, access to medical care while in crisis becomes possible. Some family carers obtained help from the medical doctor, nurse, therapist and social workers. Some experienced good help from policemen, taxi drivers, and security guards at the hospital. The difficulty in accessing medical care prompts carers to work harder on assisting their family members with mental illness to stay in stable states. Carers found different ways of helping the 'person' to get along with the 'illness' and have better quality of life. Taking back 'the right to control' in utilizing medication, from passiveness to negotiating with medical doctors and seeking alternative therapies, are seen in many carers' efforts. Besides, trying to maintain regular activities in daily life and play normal family roles are also experienced as important. Furthermore, talking with the patient as a person is also important. The authors conclude that in order to protect the human rights of persons with mental illness, it is crucial to make the medical care system more flexible and to make the services more humane: sufficient information should be provided and communicated, and efforts should be made to maintain the person's social roles and to support the family.

Keywords—Family carers, coercive treatment, independent

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living, mental health crisis, persons with mental illness.

I. INTRODUCTION

THE right to live in the community has been recognized as a basic human right for persons with mental illness. The United Nations stated in the 'Principles for the Protection of Persons with mental illness and the improvement of mental health care' that the right of autonomy and the right to freedom of persons with mental illness should be respected. Besides, least-restricted treatment in the community should be provided [9]. During a mental health crisis, nevertheless, without adequate community resources, families are often forced to choose between continue enduring the disturbing behaviors of their family members with mental illness, or sending them to the emergency unit in the medical hospital. It is common that the person with mental illness refuses hospitalization, which places some families in very difficult situations [1]. Reports show that in Taiwan, most persons with mental illness live in the community [11], and mental health crisis reporting or emergency hospitalization mostly are arranged by the family of the patient [1], [8]. Thus, in a mental health crisis, family carers are always the ones who decide whether to send their loved ones to the hospital emergency unit.

Studies found that family carers have high support needs regarding information about the illness and how to take care of their family members from a mental disorder [2], [6]. How to improve family relationships was also found as an important issue that families face [4]. Therefore, the views and experiences of family carers should be understood, in order to give them better support.

This study focuses on the mental health crisis period. Three questions are explored: 1) Under what circumstances do family carers view hospitalization as the only solution? 2) What obstacles do family carers meet, and assistance they obtain, while trying to arrange hospitalization? 3) What tips of care, have family carers learned, in caring for their family members with mental illness?

II. THE PROBLEM OF CURRENT SYSTEM

A. The Limited Resources and the Lack of Carer Support in the Community

Mental health care in the current system in Taiwan has a strong focus on providing medical care to the individual with mental illness. The current medical care for mental health persons include: emergency care, acute hospitalization, chronic

hospitalization, and daytime hospitalization. Besides, there are very limited resources of home treatment (twice per month at maximum), community nurse visits and community care visits. It was found that the case load of a community nurse was over 80 patients [7]. Apart from these medical services, no alternative services are available. On the other hand, the existing system does not provide support to family carers. Liu criticized the National Health Insurance for only paying individual medical care, while not providing carer's with vital mental health education [5]. Wu et al. found that carer burnout has been a tricky issue due to the lack of community resources and the difficulties of making coerced hospitalization into practice [10]. They emphasized that coerced hospitalization should be viewed as 'break time and space' for carers to enhance their knowledge of medicine, the illness, and the available community resources.

B. The Difficulties of Practicing Coerced Hospitalization in the Current System

Since the revision of the Mental Health Act in 2007 in Taiwan, the 'Compulsory Hospitalization and Compulsory Community Treatment Review Board' was formed. The diagnosis of two medical doctors regarding compulsory hospitalization should be sent to the review board to make the final decision. Under this law, hospitals are required to provide relevant diagnosis documents. Medical doctors were very concerned that the new system was 'much more complicated than before' and 'penalties waited to be served' [12]. According to the Mental Health Act, compulsory hospitalization could be carried out only when the individual is at risk of or is actually hurting the self or others. However, for those carers experiencing their first episode of mental crisis, it is likely they would underestimate the risks of self-injury or injuring others [3]. Thus, when the Compulsory Hospitalization and Compulsory Community Treatment Review Board adopts a strict approach in assessing the risk of self-injury or injuring others, the decision taken by the review board not to carrying out compulsory hospitalization an often lead to family carers suffering with no help [10].

Since there are very limited resources in the community to support persons with mental illness and their family carers, hospitalization becomes the only formal resource during a mental health crisis. The understanding of the situations when carers decide to send their love ones to the hospital emergency unit, and the obstacles and the assistance they obtain in the process, will help us to gain more knowledge of the nature of the mental health crisis which the individual and the families experience. In addition, learning about what carers learn from the experiences of taking care of the mentally ill family members, will be helpful for other families facing similar challenges.

III. METHODS

This study adopts a qualitative approach to answer the three aforementioned research questions. Focus group interviews were taken to collect data. In total, five focus group interviews were carried out. The participants include 24 family carers of

persons with mental illness. The mentally ill persons they care for are their mother, husband, wife, son, daughter, sister-in-law, brother, and aged from early 20s to 70s. The types of mental illness suffered by the carer's family member include: schizophrenia, obsessive compulsive disorder, and bipolar disorder. The gender and role of the participants are listed in Table I.

TABLE I
 LIST OF PARTICIPANTS

#	Gender	Role	#	Gender	Role
1	Female	Sister	13	Female	Mother
2	Female	Sister	14	Female	Sister
3	Female	Mother	15	Female	Mother
4	Female	Mother	16	Male	Father
5	Female	Mother	17	Female	Mother
6	Male	Husband	18	Female	daughter
7	Female	Mother	19	Female	Mother
8	Male	Father	20	Female	Mother
9	Female	Mother	21	Female	Sister-in-law
10	Male	Father	22	Male	Father
11	Female	Mother	23	Male	Father
12	Female	Mother	24	Male	Father

IV. RESULTS

There were three main reasons why family carers sent their family members with mental illness into hospital. In seeking hospitalization, family carers met three difficulties. Yet they also obtained some help from various actors. With lots of experiences, family carers gradually developed their own 'tips for care'. These will be illustrated in this section.

A. The Reasons for Seeking Hospitalization

1. Violence or Delusion of Being Hurt

Violence is a very common reason that participants in the study mentioned, in sending their family members with mental illness into hospital. Violence in terms of destroying things in the working places or in their houses, are disturbing to colleagues and family members. Besides, the delusion of being hurt by others, especially by family carers, was also a situation which carers found very difficult to manage on their own.

'He kept on shouting at people. He lives with my Mom. He did not sleep for the entire night. He wanted to hit me when I wanted him to stay in the hospital...He said it was better that I was hit by a car, and he wanted to set me on fire...Sometimes his eyes looked like he wanted to hit my Mom'. (2)

'She went downstairs to hit the neighbor...the chairs, tables, photos, stuff in the bathroom, the fan, the doors and the windows were all broken'. (6)

'He destroyed facilities in his company while he was working. He also destroyed things at home. He told other people that his parents wanted to beat him to death'. (7)

'He hit me, my husband, and his sister. When he is not well, he hits everyone'. (8)

'We took him out. He suddenly had this delusion that his Dad will hit him and he dared not go home'. (4)

'The more a person cares about her, the more she hates

that person. She hated me. She shouted at me. She threw away everything in the house. She threw away all her official documents and deposit books'. (9)

'He held a stick and made noises with the stick everywhere in the house. He said I wanted to hit him and kill him'. (20)

2. Weird Behavior

Apart from violence and delusions of being hurt, behaviors which are viewed as not normal and even as 'weird' also troubled family carers. Carers are often very worried by 'weird behaviors', and is another major reason why the participants of this study would decide that their family members with mental illness should be sent into hospital. These weird behavior were difficult to understand and difficult to manage, and sometimes very disturbing.

'He threw a can of salt into the water tank. He did not sleep and kept walking around for the entire night. There was a voice telling him not to use his left hand and left foot. He was worried and scared. He could not eat'. (11)

'She never used to care about politics. She used to watch news about movie stars only. But at that time she could not stop talking loudly about politics. She shouted loudly and with strong emotion. It was so loud that neighbors were bothered by the noises. She also had delusions and she shouted at me'. (13)

'He was weird. His body was frigid and he hid himself in the corner. He slept for around 14 hours a day'. (22)

'His telephone bill was 130,000 NT dollars for two months. He bought a lot of things. He was not tired and did not come home at night until two or three in the morning'. (9)

'He had this delusion that our house was on fire. He called the fire department'. (4)

3. 'Abnormal' Daily Schedule or Eating Habits

It is often assumed that normal tempo of schedule and adequate eating habits are good for one's mental and physical health. Thus, not having regular sleep and eating habits often cause concerns for family carers, and become one of the main reasons why family members take the decision to hospitalize relations who suffer from a mental illness.

'He eats a meal only per day. He sleeps a lot. Every day he sleeps for around 14 hours. When he gets up, it is already sunset. He never sees the sun. This situation continues for several months. This is not a human existence. This is not good for his health. So I persuaded him to go to stay in the hospital'. (22)

'He did not eat anything. He became very thin. Every day he did at home was keeling down on the ground'. (19)

Out of love, out of concern, and out of not knowing what to do, under these circumstances, the participants of this study found themselves having to seek hospitalization for their family members with mental illness.

B. The Difficulties Family Carers Meet When Seeking Hospitalization

There are several difficulties which family carers met, when

they tried to send their loved ones into hospital. These include: medical doctors' attitudes, the restricted responsibility area of the ambulance, and the lack of information of family carers.

1. Medical Doctors' Attitudes

Some participants mentioned that compulsory hospitalization was not a practice which each medical doctor would like to carry out. Some medical doctors insisted that hospitalization could be arranged only when the person with suffering from the mental illness signed a consent form for hospitalization. For persons who are not aware of their own illness and situation, the process of hospitalization becomes very hard. For example:

'The medical doctor said that unless your sister would like to accept our treatment, we could not force her. He said this was a human right. He said according to the law it was a human right. He told me there was nothing else he could do. I was thinking what sort of human right it is!' (1)

Another situation that was experienced in times of acute circumstance was when the medical doctor who regularly sees the patient with the mental illness, refuses to see them in an emergency because 'no appointment was made beforehand'.

'That day the doctor only saw patients who had appointments. But she was in an acute situation. We asked the doctor to see her but he refused. It broke my heart'. (6)

'Normally the doctor accepts adding-in'. (4)

'No. He asked us to see other doctors. He insisted that that day was only for appointments'. (6)

'Normally, when you know the doctor, you could add-in'. (4)

In other words, when medical doctors refuse to carry out compulsory hospitalization, and when they do not allow flexibility in seeing patients in need of urgent care, they increase the difficulties encountered by the patient and family carers and reduce the chances of the patient getting access to the necessary medical services.

2. The Restricted Responsibility Area of the Ambulance

Ambulances are not entitled to send patients to any hospital they want. Instead, each city/county has their own rules on the responsibility areas of the ambulance service. The restricted area of the ambulance was another obstacle which family carers met when seeking hospitalization. This can often result in patients not being able to see their regular, which means they are not necessarily able to see a doctor who knows the best treatment based on the history of illness, medication, and background etc. The treatment will then have to 'start from zero', which is really unnecessary and time consuming.

'The ambulance of Taipei County could not send patients to hospitals in Taipei City. So he was sent to a hospital nearby Taipei County.' (2)

3. The Lack of Information of Family Carers

On the other hand, the lack of information from the side of the family carers is another barrier. Some participants said they have little knowledge about which department of the hospital to go to, or even which hospital to go to. Therefore 'hospital-shopping' sometimes happened.

'We went to the Neurology department. The doctor told us we had come to the wrong department and so he arranged an appointment for us at the Psychiatry department. The doctor talked with my son and within two minutes he was admitted to the acute ward'. (3)

'I did not know which hospital to go to. When I felt Hospital A was not suitable for her, I sent her to another hospital. But did why she kept on leaving home? Why could her illness not be stabilized? Was it because of the medicine or because of us? I could not find the solution and I felt so tired'. (5)

'It is not a good idea to change hospitals and doctors all the time'. (3)

'Later I knew. But I did not know in the beginning. Maybe it was because she changed several hospitals and she kept leaving home and did not take her medication...'. (5)

C. The Help Family Carers Obtained While Seeking Hospitalization

Although some participants had negative experiences with medical doctors' attitudes, there were some participants who, on the contrary, had very positive experiences with medical doctors, nurses, therapists and social workers. Medical professionals could be a big help in the process of arranging hospitalization, or it could also be a barrier - it depended on the flexibility of the system and the professionals.

'The nurse and the social worker came to chat with her while we were waiting for the doctor'. (1)

'I can call the doctor, but sometimes he is very busy seeing other patients and I do not want to bother him. I have asked other therapists to call the doctor for me'. (3)

'I called the doctor and he helped to check where we could find a bed in the hospital'. (4)

'That doctor said I could join his personal 'Facebook'. He also gave me his telephone number and said I could contact him anytime. Now I send messages to the doctor when I need to contact him. That time the doctor spent a long time to persuade him to stay in the hospital'. (17)

Police could also be very helpful in some cases by making use of their authority and good skills. Policemen's help could sometimes make the process of arranging hospitalization more acceptable to the person with mental illness, and make the process easier for the family carer.

'The policeman reminded me that it was very easy that he hurt you. He said all I needed to do was to stand still and do not move my body. The policeman was angry that he was so young and how long would I make him depend on me. So that day I got close to him, and he pushed me away. So I called 119. Then two policeman and two nurses grabbed and put him onto the ambulance'. (20)

'The policeman broke the glass on the door...the policeman waited for him and escorted him onto the ambulance'. (19)

'When the police called the ambulance, he asked the ambulance to switch off the siren. I did not know what the policeman told him, but then he got on the ambulance and

in the hospital he signed the agreement to stay'. (17)

Apart from the help provided by medical doctor, nurses, social workers, the police, taxi drivers and security guards at the hospitals could sometimes play assisting roles.

'I told the taxi driver to lock the door once she got in so that she would not run away. Before we arrived at the hospital, I called the hospital. When we arrived, the security guard took her to the emergency room and I called the doctor immediately. The doctor calmed me and eased my concerns'. (1)

D. Carers Finding Their Own Solutions

Carers gradually learned good ways of managing the disease and ways of taking care of the patient with mental illness. The things they learned include: taking back control of the use of medications, ensuring the patient has activities to do and maintain family roles, listening and talking to the mentally ill person in their care, and encouraging them to go out and participate in their own daily life.

1. Making Decisions on the use of Medications

Taking medication is not a simple task. Many carers experience mixed feelings dispensing medications, while they see it as necessary, it is also worrisome. Carers developed their own ways of making use of medicines. Medication has become active decisions of the carers, rather than passive reaction towards medical doctors' decision. Some carers stopped dispensing medications without prior consultation with the patient's doctor.

'She takes more than 10 tablets per day, but the medication did not seem to have any effect. So we stopped taking the medication, but then her condition became worse'. (10)

'I thought it was like flu medication – you are fine when you are taking it. So we stopped taking the medication and her situation was no longer good'. (24)

One participant in this study, who is also a nurse, stated that she and her father adjusted the medication doses themselves; however, they also made sure this information was communicated to the doctor.

'My Dad said doctors only ask if you feel better, if you sleep well, and then decide to give you more doses. We adjust medication ourselves. We make our own assessment and we consult with the doctor. We write down the effect and side effects of the medication. We tape record and take photos and communicate that with the doctor. Now my father is able to tell immediately if one white tablet needs to be taken, just by observing small movements'. (18)

Another participant in this study even underwent training in Chinese medicine and practices and as an alternative medical treatment. He found that his wife's illness remained stabilized for several years after she began taking Chinese medicine instead.

'The side effects [of medication] are terrible. So I studied Chinese medicine myself and have used it in place of western medicine for several years'. (6)

2. Ensuring the Patient with Mental Illness Has Activities to Do and Maintain Family Roles

Apart from monitoring and administering medications, in order to ensure a patient with mental illness has something to keep them occupied, many participants in this study said that they encouraged and arranged for those in their care to learn new things such as learning to play a musical instrument or the English language, as well as taking part in different activities such as exercising, listening to music, watching TV, looking after pets, attending church meetings, attending community rehabilitation programs, and doing volunteer work. Some participants found that maintaining the 'family role' was important. Participating in a variety of activities the patient with mental illness gave them responsibilities and a sense of purpose in everyday life, and it also made them feel needed and valued by others.

'I taught him how to do housework. When I was ill, he accompanied me to see the doctor. I told him that you were the only man in the family and that we were getting old and could not lift heavy things. Luckily, we had him. How nice, isn't it...Now he does a lot of things at home'. (11)

'She had to do what she had to do in the family role. Cooking, washing clothes, and shopping were things she had to do. You could not be lazy all day and do nothing'. (6)

3. Listening and Talking to the Mentally Ill Patient in their Care

Participants gradually learned 'tips' for taking care of the family member suffering from mental illness. One of the precious tips learned by some participants was 'listening' and 'communicating'. Some participants tried to talk with the family member in their care; they talked to them about their concerns and fears, and about the voices heard by their loved ones. Through this communication, the carers were better able help ease the fears and worries in their minds of those in their care.

'I told the fortune teller what to say to him. He would sometimes get paranoid and think that other people were looking at him or making fun of him. So the fortune teller told him that he should not assume that people were focused on him or were laughing at him when they lowered their voices to talk. I also spoke with him. I told him that oftentimes there were misunderstandings. When people lowered down their voices, it only meant they did not want us to hear what they were saying, but that did not mean that they were talking about us. Gradually he accepted the idea'. (3)

'This year I started to dialogue with his delusion...a lot of delusions are not realistic...yet he was willing to talk to me about what was in his mind. To be honest, I was very scared before and did not know how to face him. But recently I...' (14)

'Her world is hectic. She once felt the outside world was not safe. I said to her: Mom, the little ghosts told you not to go outside, right? So go secretly! So my Mom

did...Mom said there were many voices and that the medication was not working. I started to learn that her world was very different from ours. So I started acting. I acted in the way that I wiped off the ghosts and said which room each 'ghost' should sleep in. Mom said she was a bad person. I said to her: Mom I love you and I say you are not. Are you going to trust me or the voices?'(18)

'She asked me whether people with mental illness could get married. I said that as long as someone accepts and looks after her it was fine. But you could not have children. I tried not to destroy her dream'. (4)

4. Encouraging Them to Go Out & Participate in Their Own Daily Life

It is common for many people who suffer from mental illness lack motivation to go out and do things. Several participants in this study mentioned the importance of encouraging a person with mental illness to go out and not stay at home all day.

'Let her go out as much time as possible. I take her on daily outings once a month'. (1)

'It is important to have normal life. Families should give him his own space and take him out. This is much better than medication'. (10)

'Drive her around or have an ice cream at Family Mart and have a chat and ask how she is'. (7)

'Let her have something to do. I said let us plan what to eat for the next week and go shopping together. So we did'. (9)

'My daughter got the illness when she was very young and did not learn to do the housework. So when she was in good spirits, I asked her to assist me with the housework such as washing and cutting vegetables, and I help her when she washing her own clothes'.(4)

V. CONCLUSION

The experiences of family carers participating in this study showed that seeking hospitalization is mostly taken as a last resort. The reasons for seeking hospitalization include: violence or the delusion of being hurt, weird behavior, and abnormal daily schedule or eating habits. These were the circumstances that family carers found most difficult to manage. As hospital is the only option outside homecare in these difficult-to-manage situations, family carers went to huge efforts to seek hospitalization.

All participants described different experiences when seeking to hospitalize their loved ones during a mental health crisis. The process of sending a loved one to hospital was seldom easy. The difficulties family carers encountered most include: medical doctors' attitude, the restricted responsibility area of the ambulance services, and the lack of information of provided to family carers. How to provide a more flexible medical system, able to better respond to the needs of patients with mental illness and their family carers is an issue that needs to be taken seriously in the future.

Although some participants spoke of frustrating experiences in communicating with doctors, several say they received the help from medical doctors, nurses, therapists and social

workers at the hospital throughout the hospitalization process. Meanwhile, others individuals who were mentioned by participants as providing valued assistance include policemen, taxi drivers, and security guards at hospitals. From the participants' experiences it is possible to build a system that integrates different roles (medical doctors, nurses, therapists, social workers, policemen, security guard) and provides a teamwork approach to crisis resolution services for persons experiencing a mental health crisis and their family carers.

Since hospitalizing a family member suffering from a mental illness was not an easy decision to make, over the years, carers have learned from their experiences and developed their own solutions. These include: taking back the power of control in administering medications, making sure the patient is active and has different interests to engage them, maintaining family roles, as well as listening and talking to the patient in their care, and encouraging them to go out and participate in their own daily life. Oftentimes family carers have tried to hospitalize the family member in their care but failed; or, in some cases, the patient discharges themselves from the hospital, and return home where the carer still has to face the ups and downs of the mental state of their loved ones. There are very few community rehabilitation centers and recovery homes available, and therefore, family carers continue to be the main source of care and undertake the biggest efforts in caring for family members suffering from mental illnesses.

Family carers, therefore, generally find their own path through their experiences of providing care. Some turned to alternative medicine; however, most carers participating in this study found that it was important to ensure the patient was active, had a role to play in the family and society, was being well communicated and being heard, and was also actively participating in their own daily life. In other words, family carers treated their loved ones with mental illness as a 'person' rather than a 'patient'.

The findings of this research have led the authors to think deeply about what it means to protect the rights of persons with mental illness. The UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care has strict rules on involuntary treatment. It was so emphasized that mental health services need to be flexible and should be provided in the least-restricted environment. The guarantee of human rights of individuals suffering from mental illness lies in a proactive medical care system and the provision of services that respect the individual as a 'human being' who deserves appropriate treatment and adequate information, communication, as well as maintaining a valued role in the family and society, and finally, by supporting the family unit as a whole.

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