

## CHAPTER IV

### FINDINGS

This chapter presents the participant characteristics, and the study findings. The objective of this study was to explore the process of caregiving for a PWS from perspectives of Thai family caregivers. To realize this objective, a semi-structured interview guide with audiotape interviews were used to gather relevant data from family caregivers. Study findings would be described as below.

#### **Demographic characteristics of the participants**

The 17 participants in this study consisted of 9 women and 8 men. Most of the participants were middle to older age, married, Buddhists, had a low educational level, lived with the PWS, and were retired or self employed. The summary of the demographic characteristics of the participant group is shown in Table 1.

**Table1:** Demographic characteristics of the participants

No	Name*	Age	Gender	Relationship with a PWS	Status	Education	Working status	Living status	Length of care
1	Pon	42	male	Husband	married	High school	Self employed	Same house	7 years
2	Jai	27	female	Daughter	single	Prathom4	Part time	Same house	15 years
3	Sang	61	female	Mother	married	Prathom4	Self employed	Same house	10 years
4	Tip	26	female	Sister	single	High school	Not working	Same house	4 years
5	Lee	34	female	Wife	married	High school	Part time	Same house	7 months
6	Wat	63	male	Brother-in-law	married	High school	Retired	Separate house	2 years
7	Mai	48	female	Mother	separated	Prathom4	Full time	Same house	5 years
8	Jom	72	female	Mother	married	Prathom4	Not working	Same house	13 years
9	Kai	50	male	Husband	married	Prathom4	Full time	Same house	3 years
10	Tong	45	male	Brother-in-law	married	High school	Part time	Same house	1 year
11	Sit	47	male	Father	married	Prathom4	Full time	Same house	7 years
12	Chai	68	male	Father	married	Prathom4	Self employed	Same house	10 years
13	Kaew	34	female	Wife	married	Prathom4	Full time	Same house	4 years
14	Boon	65	male	Father	widowed	Prathom4	Full time	Same house	4 years
15	Sri	56	female	Daughter-in-law	married	Prathom4	Not working	Same house	13 years
16	Kom	53	male	Son	married	Prathom4	Retired	Same house	10 years
17	Noy	54	female	Mother	married	Prathom4	Not working	Same house	9 months

\* All family caregivers were given pseudonyms

Table 1 presented the demographics of the seventeen families included in the study. All family caregivers were given pseudonyms. Normally the female most commonly played a role of primary family caregiver, although in this study, there were almost an equal proportion of female and male family caregivers.

The participants ranged from 26 to 72 years of age, with an average of 49.71 years old. Only two participants were under the age of 30. Most of the participants were middle-aged, 34 to 56 years old (ten participants). Five participants were over 60 years old. Two participants were in the elderly group (over 65) and were 68 and 72 years old. The length of care for each PWS varied from 7 months to 15 years, with an average of 6.43 years.

The educational level of most participants was Prathom 4 (Grade 4), which in the past was the compulsory education level. However, some young participants also completed the new compulsory education level which presently means they have to study until Mathayom5 (Grade 10). Some older participants could not read but could write their names. Five participants had high school education. However, some of them did not work and two of them were self employed.

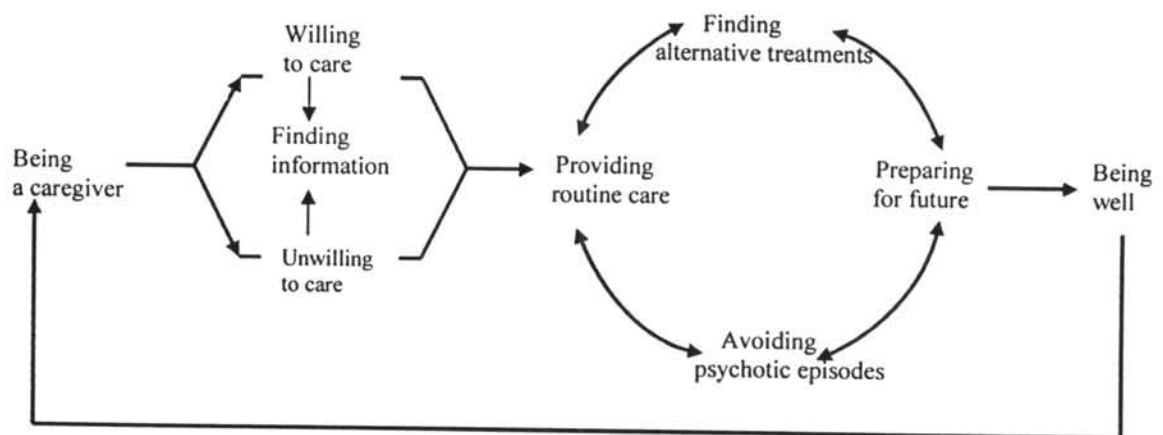
Due to change in occupations of the participants after taking care of PWS, occupations were classified into retired and reflected their current occupations (Table1). After taking care of PWS, 5 participants did not work and stayed at their home. They explained that they had switched their role to household worker because of their PWS illness.

Most participants were married (13 of 17). Two participants were single. Only one participant was separated and one participant was widowed. Most of participants (16 of 17) lived with the PWS in the same house. Only one participant lived

separately from the PWS, but his house was in the same area of the PWS. Seven participants were parents and still caring for their PWS who were their child.

## Findings

This section outlines the data analysis of phenomenon of caregiving process of Thai family caregivers for persons with schizophrenia. The research questions created for this study was: what are the processes of caregiving for a PWS from the perspective of Thai family caregivers? The qualitative findings are presented below.



**Figure 1:** A process of caregiving for the PWS

According to Figure 1, the process of caregiving for the PWS was started at “being a caregiver”. It meant that when the PWS returned home, one member in the family became a family caregiver. Being a family caregiver had 2 groups: a family caregiver who was willing to care and unwilling to care. However, both types of the family caregiver needed information about schizophrenia and how to care the PWS in order to provide appropriate care for a PWS. According to caregiving for a PWS, a family caregiver would help a PWS in 4 categories: providing routine care, finding

alternative treatments, avoiding psychotic episodes, and preparing for future. The linkage of these four categories was indicated that a family caregiver used these 4 categories back and forth in order to promote the well-being of a PWS. Details of each category would be explained as follows:

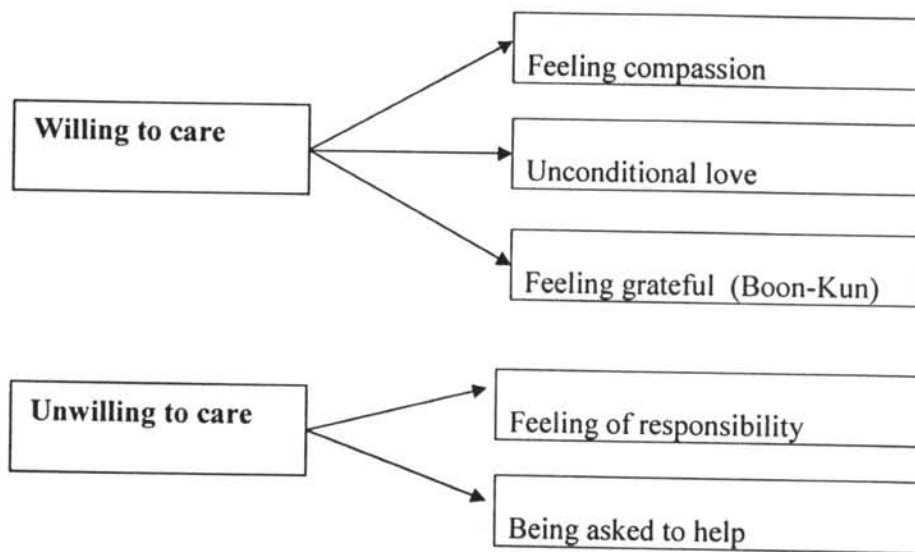
### **Being a caregiver**

When a PWS was discharged from a hospital, a member of family would take a responsibility to be a family caregiver. In this study, a father, mother, husband, wife, daughter, son, or sister was a family caregiver. Interestingly, a daughter in-law or brother in-law was also a family caregiver of the PWS. The caregiver was not assigned by the family or determined to be the appropriate family caregiver. Most of them identified themselves to assist the PWS, except 2 brothers in-law were asked by other family members to be a family caregiver of a PWS.

### **Willing/Unwilling to care**

Two different groups of family caregivers were found in the study. The first group was a family caregiver who was willing to care for a PWS without any arguments. The second group was a family caregiver who was unwilling to care but had to care for a PWS. There were several reasons the family caregiver accepted the caregiver roles.

According to Figure 2, study participants explained that the reasons of willingness to care for the PWS were feeling compassion, having unconditional love of the PWS, and feeling grateful, while the reason of unwillingness to care was the feeling of responsibility and being asked to help



**Figure 2:** Reasons of willingness/unwillingness to care for a PWS

**Feeling compassion** was a reason for wives to care for a husband with schizophrenia. Some participants explained that they decided to take care of a PWS because they loved and felt pity for a PWS to lose his social life and the ability to do things like other people. All participants (wives of a PWS) realized how happy they were together after being married. Thus, when a PWS got sick, they could not leave him alone. Lee and Kaew who took care of a husband with schizophrenia said that:

*“ ... I knew before that he was a psychiatric patient but I felt sorry for him when he got a disease. It was not his fault. He is very nice and polite. He is a good man. I don't care if someone talked something bad about him. I still insisted to marry with him. We married for 7 months. Unfortunately, after getting married, he had some psychotic symptoms: aggressive manner, restlessness, and experienced hallucinations. I was very scared of him. I thought I couldn't stay with him. I wanted to leave him but he asked me to give him an opportunity and thought about how happy we were when we lived together. So I decide to stay*

*with him because I loved him and felt pity for him. As his wife, I should stay and take care of him.” (Case 5: Lee, 5.184, 186).*

*“We were married for 9 years and we have 2 kids: 8-year old son and 4-year old daughter. Four years ago, he began to have some psychotic problems. I brought him to a hospital. The doctor told me that he had schizophrenia. This disease needed close supervision and continuous medication intake. For my deep feelings, I felt sorry for him. We (wife and kids) love him so much and want to help him to get well.”*

*(Case 13: Kaew, 13.262-279).*

**Having unconditional love** was a reason for either a father or mother to start caring for a PWS because the PWS was their child. Whatever happened to their child, they felt it had happened to them too. Although the child had psychotic behaviors and destroyed valuable things in the house, they still loved and were ready to help the PWS at all times.

*“He is my son (the PWS), only one boy in my family. Before he got sick, we (parents) planed a good future for him. We expected him to be a good man and succeed in life. Our plans were collapsed after he got sick. When he had psychotic symptoms, he destroyed everything in the house. For example, my car, I was very angry at him but I didn't punish him. I think it wasn't his fault but it was my fault. I should maintain close supervision of him more than this.”*

*(Case 11: Sit, 11.349-364).*

*“Because I am her mother, I know everything about my daughter. I understand her. I began taking care of her since she got sick. There are many people living in the house but no one pays attention to her. I cannot do like that. She is my kid.*

*I love her and I want her to get well. Whatever happens with her that means it happens to me too.” (Case 3: Sang, 3.55-77).*

**Feeling grateful** (Boon-Kun) was a reason for a son and a daughter to take care of their parent with schizophrenia. They said that parents took care of them when they were a child. Right now, it is time to pay back. They should take care of their parent as they received when they were so young.

*“She is my mom. I should take care of her. Let’s think about when I was a child, she took care of me. When something happened with her, how could I leave her? I think that taking care of her is making a merit and being a good child.” (Case 2: Jai, 2.242-246).*

*“I believed in the cycle of karma. If I do a good thing, I will receive a good thing back. Like when I take care of my dad, I am doing a good thing. ... He is my dad. Dad has Boon-Kun to me because he raised me until I could help myself, having a job and having my own house. There is no dad, there is no me. This time is paying back to him. I will take care of him until the end of my life.” (Case 16: Kom, 16.385-398).*

**Being my responsibility** was a reason of family caregivers, including a husband, eldest sister and daughter in-law, to care for a PWS. These family caregivers expressed that caring for a wife is a duty of a husband as well as a duty of a sister to care for a sick brother and of a daughter in-law to care for her mother in-law.

*“Taking care of my wife (the PWS) is my responsibility. We live separately and far from our families. After we were married, we moved to live with only us and our kids. If she gets sick, and I don’t take care of her, who else will?” (Case 1: Pon, 1,347, 456).*



*"I'm the eldest sister in my family. The other brothers are married and moved far away from home. My parents both went to work. There is no one to stay at home during the day time except me. So I have to take care of him (the PWS) and I know that he is my responsibility."* (Case 4: Tip, 4.48).

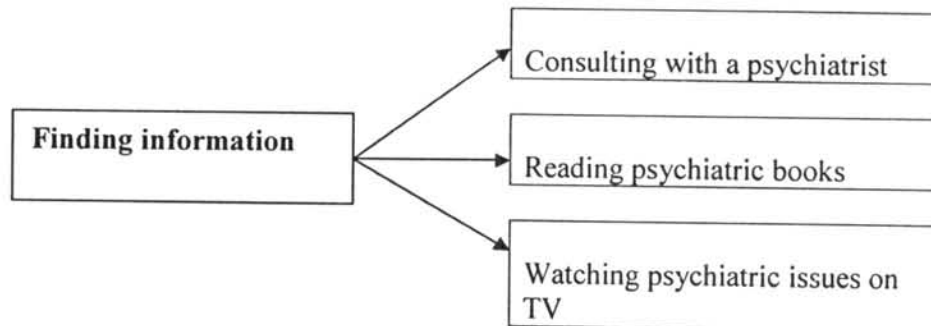
**Making a request for help.** Some family caregivers did not relate to a PWS by blood lineage but were asked to help other family members to relieve the burden. A brother in-law had to accept a caregiving role because he wanted to help his wife and another brother in-law was asked to care for a PWS because he was the only one a PWS talked with.

*"He (the PWS) is a psychiatric patient and he doesn't do anything to help himself. Other members in our family include my mother in-law, my wife, and me. My mother-in-law is 84 years old. She isn't healthy enough to take care of her son. My wife tells me that she feels sorry for her mother and tries to help her to take care of him all the time. Unfortunately, my wife has to work outside of the house. Thus it is only me available for the PWS. So I take care of him to relieve the burden from my wife and my mother-in-law."*  
(Case 6: Wat, 6.286-292).

*"In our house, all of family members are female but me. And the PWS is a male. No one understands him except me (a brother in-law). In caring for a PWS, if you don't understand him, you cannot take care of him well. My brother (the PWS) will not talk with anyone except me. Thus, everyone in my family asked me to care for him. I have to accept that role."*  
(Case 10: Tong, 10.314-330).

### Finding information

After a family member accepted a role of a family caregiver of a PWS, all of them found any information to increase their knowledge of schizophrenia, both the disease itself and how to take care of a PWS. Three sub-categories of finding information emerged in this study were consulting with a psychiatrist, reading psychiatric books, and watching psychiatric issues on TV.



**Figure 3:** Sub-categories of finding information

**Consulting with a psychiatrist.** Family caregivers would consult a doctor (a psychiatrist or nurses) at the beginning of being a caregiver and during the period of caregiving. In the beginning of care, they asked a doctor about what schizophrenia was, how to take care of a PWS, and how long until a PWS would get well. Later on, when a caregiver had difficulties of caring for a PWS, they would consult a psychiatrist or nurse regarding the issues of ineffective medications to control psychiatric symptoms, and strange behaviors performed by a PWS.

*“He acted as a violent person! I took him to a hospital. When a doctor told me that my son became ill with psychotic symptoms, I was very shocked! I don’t know why it happened to him. I have no idea of what the illness is. I asked a doctor (a psychiatrist), and she explained it to me. The doctor told me how to take care of him. She told me that how important*

*the medications were! Giving medication regularly is one way to help my son control his psychiatric symptoms.*

(Case 11: Sit, 11.64-79).

*"I talk with a doctor very often when she (a PWS) doesn't open her eyes after taking medications. She sleeps all the time. I don't know what happened to her. I shake her arm and leg. She didn't respond. I tried to wake her up several times. ... When she woke up, she was in the bad mood, so I went to the hospital and asked her doctor. The doctor explained that she sleeps all the time because of the effect of medication intake. Thus, the doctor changed the amount of medications for her. (Case 17: Noy, 17.106-112).*

*"My husband refused to take his medication. I asked him to do so and explained him that how medications are important to him. But he didn't listen to me. He didn't want to take them. I didn't know what to do. So I went to talk with the doctor. He told me that "you can find any tricks to give him medications." When I went home, I thought about the way to give him medication. Then, I just have an idea to mix medications in his food. When I cook food for him, I dissolve medications into his food. He didn't know about it."*

(Case 13: Kaew, 13.317-325).

**Reading psychiatric books.** Some family caregivers found information of schizophrenia by reading psychiatric books, pamphlets, and brochures in order to make sure that they had enough knowledge to care for a PWS.

*"Normally, I like reading books. After I became his caregiver, I read psychiatric books to learn the way to take care of this patient. Sometimes, when I came to the hospital, I read a pamphlet (of schizophrenia) and I applied some of the advice to care for him." (Case 6: Wat, 6.473-493).*

*"When taking care of her at home, I don't know how I should care for her. Every time we go to hospital for a doctor's appointment at OPD, I look for something to read while waiting for her queue. I see a brochure of schizophrenia. So I take one to read. It helps me to gain knowledge to take care of her."*  
(Case 7: Mai, 7.269-281).

**Watching psychiatric issues on TV.** Some family caregivers learned about schizophrenia from TV programs including movies, dramas, and talk shows which provided information about psychiatric treatments, signs and symptoms, and psychological health. Getting more information of the disease made a family caregiver confident to care for a PWS.

*"I learn to care for him (a PWS) by watching psychiatric issues on TV. At first, I didn't pay attention about these issues. But when I have to take care of a PWS, every issue of schizophrenia interested me. For example, I watched "Lang-Kha-Dang" (a drama of a madman) and a health issue of schizophrenia from a TV show. It showed me how to calm down my PWS."* (Case 4: Tip, 4.138-143).

The caregiving process usually started when the PWS was returned to their family. Family caregivers usually provide care for a PWS from dawn until dark. It is a continuous job for 24 hours a day, 7 days a week, and 12 months a year. In this study, the family caregiver performed 4 categories of caregiving activities: providing routine care, finding alternative treatments, preparing for the future, and avoiding psychotic episodes.

Providing routine care for a PWS in each case might have involved different or similar activities, but all of them had the same purpose of organizing the personal life of a PWS as a healthy person did. Study participants shared their experiences of providing routine care of a PWS as follows: washing clothes, taking him/her to the bathroom, preparing/cooking food, and giving money for daily expenses.

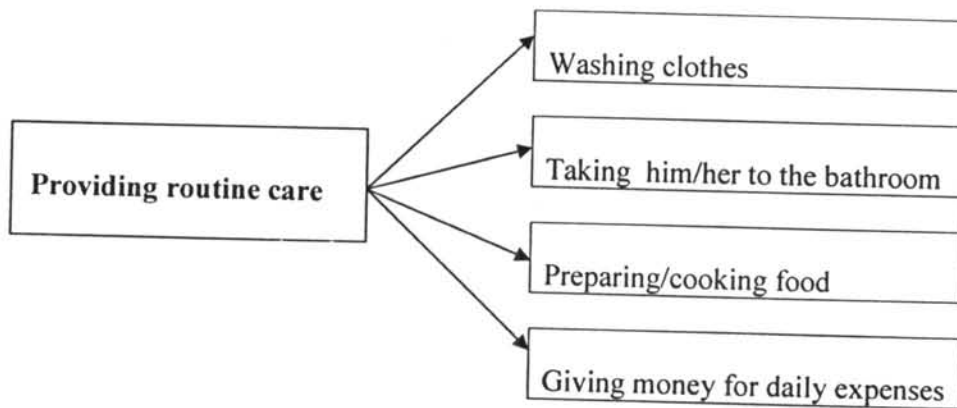


Figure 4: Sub-categories of providing a routine care

**Washing clothes.** Some participants assisted their PWS to wash clothes for different reasons. In this study, a husband (Kai) reported that his wife (the PWS) did not pay attention to anything while a mother (Mai) reported that she wanted to share responsibilities of housework with her daughter (a PWS).

*“Sometimes, I wash clothes for her (the PWS) because she doesn’t pay attention to clean them. When she takes off her clothes, she throws them away. If I don’t do it, she will not have clothes to put on.” (Case 9: Kai, 9.146-162).*

*“I have to help her to do many things. For example, when I saw her exhausted from work, I felt pity for her. So, I wanted to help her with her housework such as washing her clothes. Sharing responsibilities with her will allow her to*

*have time to relax. She will be happy and have time to drink soy milk, watch TV and play computer games."*

(Case 7: Mai 7.298-305)

**Taking him/her to the bathroom.** Some participants reported that the major routine care they assisted was taking a PWS to the bathroom. In particular, when a PWS had psychotic symptoms, he/she would not do anything, including cleaning him/herself.

*"When she has psychiatric symptoms, she doesn't want to do anything, even personal care. I have to take her to the bathroom, and tell her to clean herself. Then I help her to change her clothes." (Case 17: Noy, 17.162-178).*

*"I have to help her (the PWS) to arrange many things. In the morning, I wake her up and I take her to the bathroom. I have to tell her to brush her teeth, take a bath and change her clothes." (Case 15: Sri, 15.162-181).*

**Preparing /cooking food.** Another routine care the family caregiver assisted a PWS was preparing or cooking food for a PWS. For example, a wife of a PWS said that:

*"After we (the PWS and the wife) went back from work at 1 am, we talked until 4 am and then went to bed. We woke up again at 4 pm. We went to grocery together to buy things for dinner preparation. I (the wife) cooked food for him. He loved to eat the food I cooked." (Case 5: Lee, 5.168-175).*

*"I cook food for her but sometimes I went to buy food that she wanted to eat. If she gets sick, I have to feed her and make sure that she ate her meals." (Case 2: Jai, 2.74-94).*

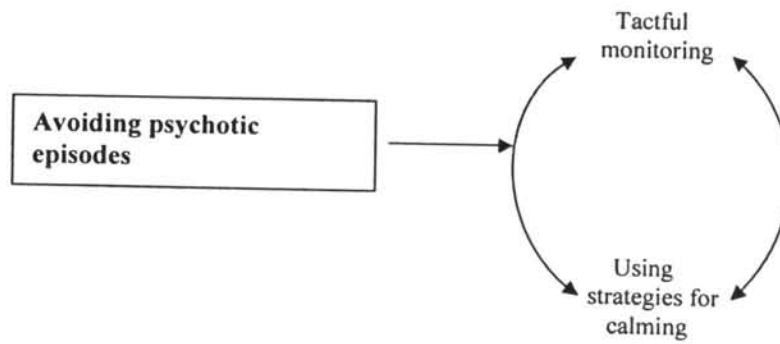
**Giving money for daily expenses.** Surprisingly, some family caregivers of a PWS reported that providing a routine care for them referred to giving some money to the PWS for his/her daily expense.

*“Because of my daughter (the PWS) is unemployed, she has no income. I (the father) have to give her money to buy her personal things. I compared her with myself, if I don't have money, I will feel bad. So I give her money, 200-500 baht every day. In fact, she doesn't buy anything but she feels happy to have money in her hand.”* (Case 14: Boon, 14.399-413).

*“We (parents) have a business of packing sweet tamarinds. She (the PWS) helped us to pack the tamarinds. Although she does not work, we gave money to her every day in case that she wants to buy something, she can buy it.”*  
(Case 3: Sang, 3. 253-271).

#### **Avoiding psychotic episodes**

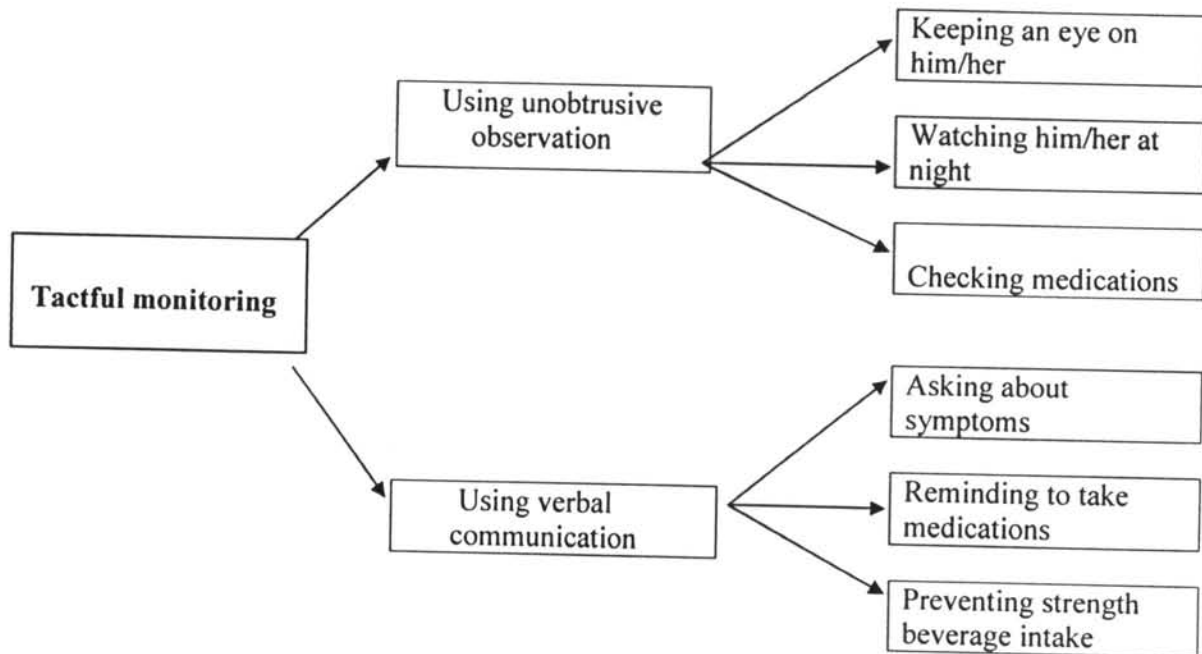
Avoiding psychotic episodes was another category important in caregiving for a PWS. According to experiences of the family caregiver, when a PWS had psychotic symptoms, he/she could not control him/herself, nor could the family caregiver control the PWS. Thus, the family caregiver tried to prevent unexpected psychiatric symptoms of a PWS in order to avoid psychotic episodes from happening again. The two categories of avoiding psychotic episodes that emerged in this study were: tactful monitoring and using strategies for calming down. These categories were used back and forth depending on what kinds of caregiving situation occurred. For example, if a PWS did not have psychiatric symptoms, a family caregiver would use tactful monitoring to observe a PWS. But if a PWS showed some psychiatric symptoms, the family caregiver would use strategies to calm the PWS down.



**Figure 5:** sub-categories of avoiding psychotic episodes

### **Tactful monitoring**

Tactful monitoring was emerged from the data in the caregiving process of Thai family caregivers for PWS. Tactful monitoring was defined as the strategies the family caregiver evaluated the development of the illness of the PWS. Two strategies used were: unobtrusive observation and verbal communication.



**Figure 6:** sub-categories and themes of tactful monitoring



### Using unobtrusive observation

In general, no one wanted others to look at the PWS for a long time without moving their eyes. Like a PWS, he/she did not want a family caregiver to stare at her/him. Due to the suspiciousness of occurring psychotic episodes, a family caregiver had to do something to prevent those events. Most family caregivers in this study shared their experience of using unobtrusive observations including keeping an eye on the PWS, watching him/her, and checking medications.

**Keeping an eye on him/her.** Some family caregivers reported that sometimes psychotic medications could not control psychotic behaviors of a PWS. The PWS was confused and exhibited strange manners. The family caregivers could not ask anything from the PWS. Thus the way to check ill conditions of a PWS was keeping an eye on him/her. In case that something happened, the family caregiver would be able to deal with a difficult situation on time.

*“For her illness, I keep my eyes on her manners. I use the corner of my eye to look at her. When I see that she does something wrong, I will use voice “Hmm! Hmm!” and she knows that she made some mistake.” (Case7: Mai, 7.300).*

*“I think that keeping an eye on her helped me to evaluate whether a PWS did something wrong or not. Normally we talked together but someday she is confused and exhibits strange manners. I have to know when this happens and take her to see the psychiatrist as soon as possible.” (Case14: Boon, 14.324).*

*“It is difficult to talk with him (the PWS) because he isn't normal. When his psychiatric symptoms happened, he didn't do anything. He sat and remained silent and then he used his hand or something solid to smash a glass cabinet and mirror. I don't want*

*something like this to happen again. So I should keep my eyes on him.”*  
(Case 4: Tip, 4.198).

**Watching him/her at night.** Some family caregivers stated that observing a PWS’ behaviors during the day time was not enough to care for a PWS. They realized that psychotic episodes could occur at all times. Thus, the family caregivers were required to stay at the same room of a PWS in order to observe psychotic symptoms.

*“...I’m her mother. I take care of her (the PWS) more than the others in our family. I knew that psychotic episodes can happen during day or night. I want to observe her throughout the 24 hrs. Thus, I sleep in the same room with her every night since she got sick.”*

(Case17: Noy, 17.65).

*“Because I sleep in the same bed with her, I noticed that she had some symptoms. She made some noises like Chu..Chu..Chu., she groans and says that what is it? Sometimes, she is restless therefore she cannot sleep so well at night.”* (Case2: Jai, 2.108).

**Checking medications.** Some family caregivers reported that medications of a PWS made them confused because these medications were not taken in the same dose and at the same time frame. These caused the caregivers to realize the responsibility of checking the right dose and time of medications for a PWS. In addition, some PWS did not want to take medication. The family caregiver required to check medications of a PWS by counting the pills.

*“Sometimes I don’t ask him anything about his pills but I check his medicine bag to find whether he takes the medication or not. Sometimes he tells me that he takes it, but when I check his medicine bag to make sure, he didn’t take it. If I’m busy I cannot remind him anything today, I will check his medicine bag the next*

*day. I count the pills and I will know whether he took it or not.”*  
(Case6: Wat, 6.196).

*“...I have to check his medication at all times and I have to check the right dose and time for him. The PWS has to take 4 tabs in the morning, 3 tabs after lunch and 6 tabs in the evening. Sometimes I am confused about the medication doses.”* (Case11: Sit, 11.118).

#### Using verbal communication

Beside, using unobtrusive observation, family caregivers talked directly with the PWS in order to check on medication intake and symptoms of the PWS; and to reduce strength beverage intake which caused an increase of psychotic behavior of a PWS. Three sub-categories emerged in the study were asking about symptoms, reminding to take medications, and preventing strength beverage intake.

**Asking about symptoms.** Family caregivers thought that if they wanted to know about his/her illness, they would ask the PWS directly about how they felt with their illness or if they hear any voices talking to them.

*“... I ask her (the PWS) about her illness after having dinner. “How do you feel today? She will tell me and talk something else. If her answers related to my questions, it indicates that she is still OK now.”* (Case14: Boon, 14.211).

*“ ..Sometimes, she smiles with her self. She often sits alone and her eyes look blank. If I see that, I will ask her. How are you, or how do you feel? I used to ask her all the time.”*  
(Case7: Mai, 7.254-266).

**Reminding to take medications.** The important problem which family caregivers met when they took care of the PWS was reminding the PWS to take

medications. The PWS often forgot to take it regularly and some PWS thought that they did not need any medications because they felt better.

*“He often forgets taking his medication but not too much. Two-three days ago I went to work and came back in the evening. When I asked him about his medication, he just went to his room to take it.” (Case 6: Wat, 6.330).*

*“... I tell her to take medications, but sometimes she forgets and I have to warn her again. Her dose is just only one time per day. See how come she can forget it.” (Case7: Mai, 7.241)*

*“I let her take care of herself but in the evening I have to remind her “Aun (a Pseudonym), did you prepare your medication in your bag?” “Be careful! if you forget it, you will get sick again. Remember! Your doctor told that you have to take it regularly.” (Case17: Noy, 17.265).*

*“... He doesn't take it in that time. He still takes his medication as he wants. So I have to remind him to take it.” (Case5: Lee, 5.356).*

**Preventing strength beverage intake.** Most family caregivers explained that the PWS tried to hide and drink strength beverages such as Kratingdang, Lipo, M150, Look-Toog, and coffee. The PWS drank strength beverages despite the fact that they affected their emotional changes and made them have psychiatric symptoms. The family caregivers tried to warn a PWS to stop drinking strength beverages. Some prohibited their PWS from drinking strength beverages.

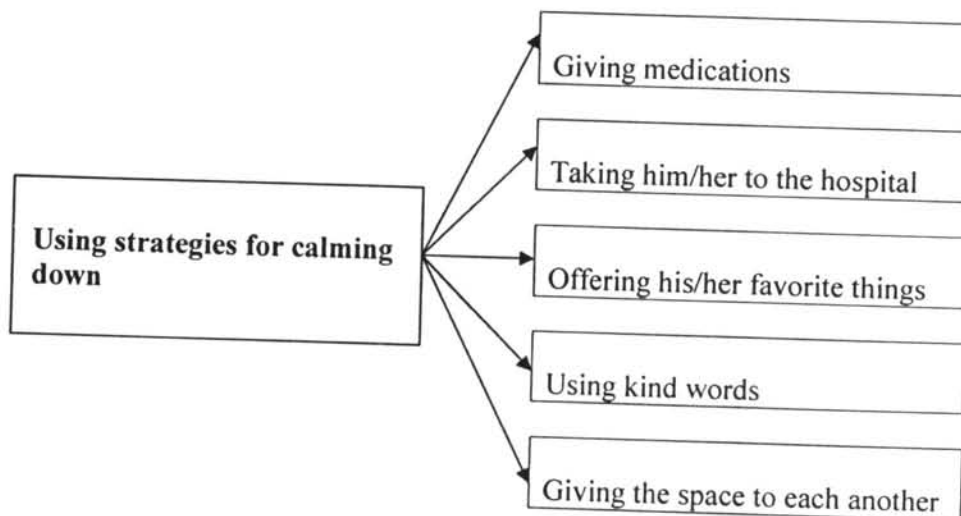
*“In January, we visited to Chaing-mai province. He (the PWS) drank a lot of bottles of coffee. He stayed up late because coffee made him wake up all night. In the morning, his symptoms were bad. Another time, he began to have psychiatric symptoms again after drinking strength beverages. I tried to stop him from drinking but he*

*never listened to me. Sometimes, I have to hide the strength beverages.” (Case5: Lee, 5.341)*

*“... I think that drinking alcohol and strength beverages affected his illness. He (the PWS) loves to drink them. I try to prohibit him to drink them but it is very difficult to do so. Because my house has a store, he often picked up some bottles of alcohol and strength beverages to drink. If I don't hide the strengthened beverages from him, he would drink a lot.” (Case12: Chai, 12.275)*

### **Using strategies for calming down**

Schizophrenic symptoms included hearing strange voices, seeing imagined people, talking alone, thinking they are threatened by dangerous people, and losing the ability to concentrate to do anything. Sometimes a PWS showed violent behaviors. The PWS might go on a rampage, fight other people, and break things. Family caregivers have to understand and use appropriate strategies to deal with those symptoms. All family caregivers shared their experience of using 5 strategies for calming a PWS down. Those were giving medications, taking him/her to hospital, offering his/her favorite things, using kind words, and giving the space to each another.



**Figure 7:** Sub-categories of using strategies for calming down

**Giving medication.** During caregiving for a PWS, family caregivers often dealt with psychotic events of the PWS. All family caregivers reported that the first thing to calm down a PWS was giving them their psychotic medications. Like, Jai and Sit explained from their experiences:

*“If she (the PWS) had strange manners, I know that she needed medications. I gave her medications and observed her for a while. Then she changed her strange manners to be normal. Sometimes If I go out, I will tell my elder sister to give her medication and stress that that “doesn't forget to give her medication”. (Case2: Jai, 2.203)*

*“I think that psychiatric medications are important because it can control his emotion. If he doesn't take his medications 1-2 times, he looks like a violent person and after that I cannot control him.” (Case11: Sit, 11.69).*

**Taking him/her to hospital.** While taking care of a PWS, family caregivers had to observe and understand how to deal with psychiatric symptoms of the PWS when they performed strange and aggressive manners. If psychiatric medication could not control or reduce psychotic symptoms, the family caregiver had to take a PWS to the hospital.

*“Sometime if he (the PWS) is violent, I will take him to a hospital... Although it is in the night time, I have to take him there. At the hospital he received medications. Usually, when he looks to run wild, I will take him to the hospital, even at the night time...” (Case11: Sit, 11.70, 11.81).*

*“She is stubborn. She doesn't listen to my words. She is aggressive and fights other people. In this situation, I cannot control her. So I take her to the hospital. The doctor has to admit her in the hospital and give her medications. After she calms down, the doctor*

*allows her to go home and tells me to bring her to the hospital again for an appointment.” (Case 3: Sang, 3.107-116)*

**Offering his/her favorite things.** Some family caregivers had their own strategy which they found during caregiving for a PWS. That strategy was offering the PWS their favorite things. Study participants disclosed that sometimes a PWS ran away from home either if he/she did not get things he/she wanted or had psychiatric symptoms. Sang indicated that giving money was the trick to calm a PWS down whereas Sri cooked the favorite food for the PWS while waiting at home.

*“She made a lot of demands and there are a lot of things she wants. I had to find them for her, if not, she gets mad. I had to spoil her. Everything is including money and stuff. If she asks, I had to give them to her. I had to give her money every day at least 200 baht. She will spend money with nonsensical things. Sometimes, she gets more stressed. She asked for more than 1000 baht to shop. Her emotion will calm down after going shopping.” (Case 3: Sang, 3.148-165)*

*“When she (the PWS) has psychiatric behaviors, she ran away to her sister's house located near my house and she didn't return home for 3 days. I went to see her and invite her to return home. She refused. I know that she loves to eat, so I cook her favorite food. I tell her that “everything that you want, it's ready in our house...If you want to eat food, please go home with me. I let you eat all as you want.” She listens and then goes home with me.” (Case15: Sri, 15.417).*

**Using kind words.** Some family caregivers explained that the PWS would get mad if some people spoke angrily or shouted at them. Thus, family caregivers often talked gently with the PWS. Like, Jom, Wat and Sri that used this strategy to calm down their PWS.

*"I have to talk with him (a PWS) by using kind words and speak pleasingly. I don't speak angrily. If I shout at him, he will get angry...If I want him to do something for me, I have to talk with him by using kind words. He will help me to do things." (Case8: Jom, 8.167).*

*"The first thing, family caregivers should calm the PWS down because the PWS aren't normal like other people. Using kind words will not make the PWS upset. I think that this is very important to take care of the PWS. If he calms down, you can tell them to take medication and then they will pass their terrible time...It looks like a successful chain to take care of their PWS." (Case6: Wat, 6.508).*

*"For caring for her psychological part, I used kind words to talk with her. It is important and I have to speak softly with her. If she wants anything, I will ask her with soft words. If I don't use that kind of words, she will think that I speak sarcastically at her. Then, she will perform bad behavior to respond to my words." (Case15: Sri, 15.550).*

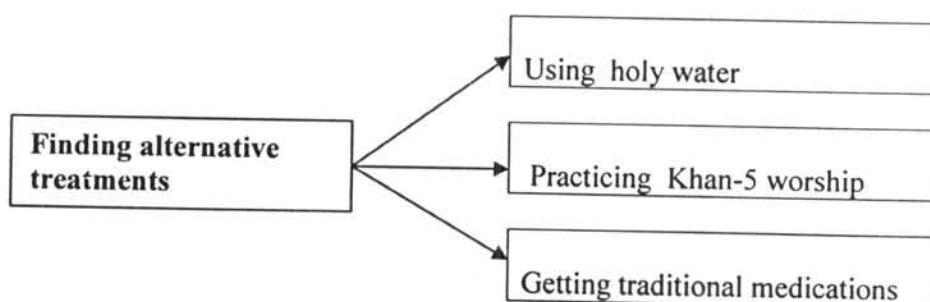
**Giving the space to each another for a while.** When the PWS became seriously ill or got angry when staying at home because of their psychiatric symptoms, they showed their aggressive manners to their family caregivers. The family caregivers experienced stressors and bad moods, but they had to remain calm in order to calm the PWS down. Going far from the PWS helped family caregivers to control their mind before returning to care for PWS again.

*"When she (the PWS) got mad or angry, she blamed me. If she is furious, she takes off her shoes and throws them at my face (trembling voice). It makes me get mad with her. At this time, we need our own space to calm ourselves down. I will go one way and she will go another way. After we both calm down, I will go back to talk to her again." (Case15: Sri,15. 321)*



### Finding alternative treatments

In the beginning of caregiving for a PWS, some family caregivers hoped that a PWS would return to be normal. Thus, whoever suggested other treatments to cure schizophrenic symptoms, the family caregivers would find those treatments which might help the PWS. The alternative treatments referred by study participants in this study were using holy water, practicing Khan-5 worship, and getting traditional medication.



**Figure 8:** sub-categories of finding alternative treatments

**Using holy water.** Using holy water was an alternative treatment relating to religious beliefs. Thais believe that holy water is sacred and able to wash bad things away from human. In this study, some family caregivers mentioned that their neighbors suggested him to take a PWS to see a monk for religion treatments: sprinkling with holy water and drinking the holy water.

*"I brought him to get a treatment from many places such as a temple. My neighbors suggested me to bring the PWS to see a monk for religious treatment. He might get better. I thought that there was nothing to loose. So I took him there and the monk sprinkled holy water on him. In addition, I brought a bottle of holy water for my son to drink. I think it can help him to be a normal."*

(Case 11: Sit, 11.317-323).

**Practicing Khan-5 worship.** It is a supernatural belief that family caregivers used to help their PWS. Khan-5 worship is a ritual consisting of putting flowers, a candle and incense sticks in a small bowl to worship a shaman in order to dispel bad things out of a PWS' body.

*"His symptoms made me think that there was somebody inside him. He cut his hair without reason. Sometimes he put Thai custom on like he is a god. Neighbors told me that a ghost occupied his body and suggested that I take him to practice Khan-5 worship (using a small bowl containing flowers, a candle and 3 incense sticks for holy objects' worship. Then we brought it back home for worshipping."*

(Case 12: Chai, 12.59-64)

*"After she (the PWS) got sick, she was talkative. She talked all day and all night long. She looked like she had somebody in her. My neighbors told me that there was a baby ghost into her body. They suggested I go to see Mhor-pee (a shaman) to participate in Khan-5 worship."* (Case 9: Kai, 9.67-74)

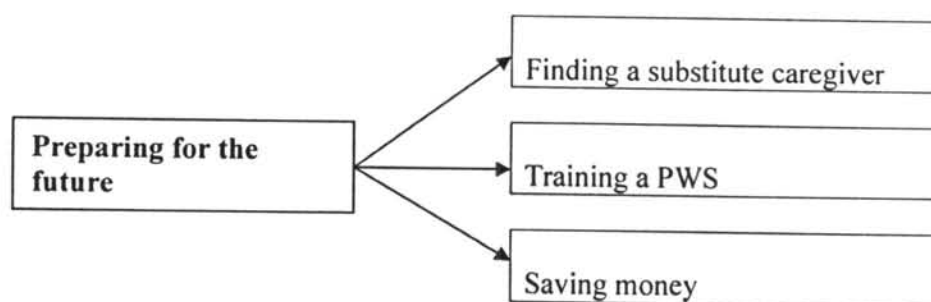
**Getting traditional medications.** Some family caregivers find an alternative treatment like "yah-mau" (decoction) which was traditional medicine. They believed that traditional medicine would excrete bad things from the PWS' body. Like Pon who believed in "yah-mau" said that:

*"Her symptoms were hallucination, talking to herself, and so on. I took her to see the monk. The monk gave "yah-mau" for her. I brought it home and boiled it for her drink. I thought that the medication would help her to excrete bad things out of her body."*

(Case 1: Pon, 1.84-108).

### Preparing for the future

Caregiving for a PWS was not just only the responsibilities for the present time, but also preparing for the future of a PWS. After family caregivers got more experiences of caregiving for a PWS, they realized that schizophrenia was not curable. That meant their relative would live with schizophrenia throughout their life. Thus to promote well being of a PWS, family caregivers prepared something for a PWS. Preparing for the future in this study was finding a substitute caregiver, training a PWS, and saving money.



**Figure 9:** sub-categories of preparing for the future

**Finding a substitute caregiver.** Some family caregivers who were the parent of a PWS often worried about the daily livings of a PWS because they realized that they could not live long. They, thus, tried to find someone to be a substitute caregiver for a PWS.

*“There are only 3 persons (Father –mother –brother) in the family to plan for her future. For my son, he plans to build a new computer shop for her. I am not worry about her any more. If I pass away, her brother will take care of her instead of me.”*

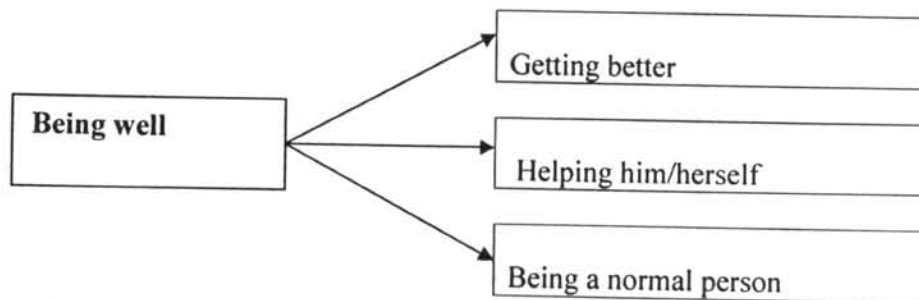
(Case 17: Noy 17.551-557)

*"I am very concerned. I am very worried if his mom and I cannot take care of him, who can do as same as I do? He has 2 elder sisters and a little nephew, but I am not sure they can help my son or not. I have to find someone to help him instead of me." (Case 11: Sit 11.367-394)*

*"I am so worry about who will take care of him if my wife and I pass away. I think that he knows this. He tries to find someone to take care of him but he cannot find one now. Sometimes, he complains that maybe he will become a monk if he lives alone. He just plans for himself." (Case 12: Chai, 12.219-226)*

### **Being well**

Family caregivers devote their time to caring for a PWS in order to enhance well being of a PWS. The meanings of being well in this study were getting better, helping themselves, and being a normal person.



**Figure 10:** sub-categories of being well

**Getting better.** Some family caregivers did not want to set high expectations for a PWS because they now knew that schizophrenia cannot be cured. They just only wanted the PWS to get better. Getting better was referred to as performing good

behaviors including talking reasonably, answering relative to the question asked, and making a connection with others.

*"To compare his symptoms between before and now, I think he is better than 5 months ago. He looks like a normal person. Last time he isolated himself and didn't go anywhere but now he changed unexpectedly. He is very good and very well now. However, my responsibility has not ended yet. I still have to take care of him but not too much as I did before." (Case 4: Tip 4.160-167)*

*"I prayed for him. I wished he would not be aggressive talk with himself. I don't expect that he will get well. I know that this disease is not curable. The doctor told me that he has to be controlled by medication his whole life. Anyway, I am ok if he doesn't perform psychotic behaviors. Although he has gotten better, I am still his caretaker. You know, he still needs someone to lean on! (Case 13: Keaw 13.279-287)*

*"I don't believe that he will get well. He cannot return to be the same person. I do not expect he will be better than this. I think that his symptoms can be controlled now. That is Ok for me." (Case 10: Thong 10.509-516)*

**Helping him/herself.** Some family caregivers wished their PWS could help him/herself for personal care and ability to do things in his/her basic life. Because they realized that no one can help the PWS forever, they tried to train a PWS to do things by him/herself.

*"I mean that if she can take care of herself...just her personal care. I am Ok. I don't expect that she have to be able to do housework. I think she is better than the previous time. I trained her little by little. Right now I don't have to encourage her to do things more and more.*

*She can get off from a bed, clean herself and eat food without telling her to do.*" (Case 1: Pon1.397-411)

*"I am sure that his illness cannot be cured. Therefore I want him to be able to help himself for his daily activities and help me with some kinds of housework. You know, I wait for 7-8 years to see my son gets better but his progress is very slow. I used to hope he would become the normal guy but right now I can accept that he will not become the same guy as I knew before. Therefore I trained him to do his personal things and he can do that now."* (Case 11: Sit 10.379-388)

**Being a normal person.** Some family caregivers still wished that when taking care of a PWS, they wanted the PWS to be normal like the others people. It meant that the PWS has no psychiatric symptoms and lived like a normal person.

*"I would like him to get well, so I take him to follow up and I give him medications regularly. Now he can help me to do housework."* (Case 8: Jom, 8.330-346)

*"I want him to be well and he can do many things the same as he did before he got psychiatric symptoms."*  
(Case 12: Chai, 12.352-361)

*"Yes, I want her to be cured. She can help herself to do many things and she can work. If she becomes a normal person, she can work and have her own money. She will be very happy."*  
(Case 14: Boon, 14.416-428)

The chapter described the family caregivers' demographics and study findings. In this study, seventeen participants explained their experiences of caregiving for a PWS. The process of caregiving for a PWS was analyzed for the study. The caregiving process consisted of 8 categories including: being a caregiver, willingness/unwillingness to care, finding information, providing routine care, avoiding psychotic episodes, finding alternative treatments, preparing for the future and well being. The caregiving process was started when a PWS returned to home after being discharged from hospital. One family member was required to be a principal family caregiver. In this study, 4 mothers, 3 fathers, 2 husbands, 2 wives, a sister, a son, a daughter, a daughter in-law, and 2 brothers in-law became the family caregiver of a PWS.

Those family caregivers were divided into 2 groups: willing and unwilling to care for a PWS. Family caregivers who were willing to care for a PWS explained that they felt either compassion, unconditional love, or grateful with a PWS. Family caregivers who were unwilling to care for a PWS explained they thought it was their responsibility and some reported that other family members asked them to do so. After family caregivers accepted to care for a PWS, they tried to find any information about schizophrenia to gain their knowledge and increase self confidence to care for a PWS. Consulting with a psychiatrist, reading psychiatric books, and watching psychiatric issues on TV were various methods family caregivers used to find information.

When family caregivers gained more knowledge to care for a PWS, they began to work as the family caregiver by providing care for 4 categories: providing

routine care, avoiding psychotic episodes, finding alternative treatments, and preparing for the future. Providing routine care was helping a PWS with daily life activity consisting of washing clothes, taking him/her to the bathroom, preparing/cooking food, and giving money for daily expenses of a PWS. Avoiding psychotic episodes was referred as the prevention of psychiatric symptoms might occur during the period of care. Two major strategies used by family caregivers were tactful monitoring and using strategies for calming down.

Tactful monitoring was investigating psychiatric symptoms of a PWS by using observations: keeping an eye on him/her, watching him/her at night, checking medication, verbal communications including asking about symptoms, reminding to take medications, and preventing strength beverage intake.

Using strategies for calming down was methods family caregivers used to calm the PWS down when they performed psychiatric behaviors. Giving medications, taking him/her to the hospital, offering his/her favorite things, using kind words, and giving the space to each another were strategies family caregivers used to calm the PWS down.

Finding alternative treatments was another category of caring for a PWS in order to seek traditional treatments beyond scientific medications. Some family caregivers reported that they wanted the PWS to get well. If there were any ways to cure the PWS, they wanted to try. Using holy water, practicing Khan-5 worship, and getting traditional medications were alternative treatments family caregivers used.

Preparing for a future was a part of caregiving for a PWS. Due to nature, obviously no one can live forever. Thus, some family caregivers prepared for the future for the PWS. Finding a substitute to care for the PWS, training him/her to help



him/herself for personal care and other daily life activities, and saving money for a PWS to spend in the future were reported by family caregivers.

Being well was an expectation of family caregivers when caring for a PWS. Well being in this study meant getting better, helping themselves, and being a normal person. Although a PWS showed signs of improvement, family caregivers still cared for the PWS because they knew that their schizophrenia was not cured. Persons with schizophrenia still needed continuous care from the family caregiver.