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LIVED EXPERIENCES OF FAMILY MEMBERS WITH CHILDREN WITH MALADAPTIVE BEHAVIOR: INPUTS TO MENTAL HEALTH AWARENESS

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ABSTRACT

This study explored the essence of the lived experiences of family members with children with maladaptive behavior who have been diagnosed with paranoid schizophrenia in Bengkulu Province, Indonesia. It aims to enumerated and specified the challenges in caring for a child with paranoid schizophrenia and the study cited how family members cope with the challenges.

The participants of this study were family members who have children with maladaptive behavior specifically those diagnosed with paranoid schizophrenia at Bengkulu Province-Indonesia. A total of ten (10) family members purposively selected either the children's parents or their sibling were the participants of the study. They were selected according to the following criteria: (1) family members of children diagnosed with paranoid schizophrenia presently admitted for a minimum six month in a Mental Hospital in Bengkulu Province in Indonesia and (2) those who were willing to consent and participate in this study.

The study utilized a qualitative phenomenological approach in exploring the lived experiences of family members with children diagnosed with paranoid schizophrenia. The sample consisted of male and female between twenty one (21)-seventy four (74) years old.

The transcripts from the interview revealed two general themes namely: 'Challenges Encountered' which included feelings of being ashamed, stressful condition, anxiety, worry, sadness, and burden in life. And 'Coping' which included spiritual approach, support groups, available alternative, optimism, positive outlook in life, and love of parents.

Based on the findings of the study, the following generalized conclusions were drawn:

(1)Family members faced social stigma, emotional and social difficulties in caring for their children which leads to experiences of feelings of being ashamed, stressful condition, anxiety, worry, sadness and burden in life; (2) In addressing the challenges, family members adopted coping mechanisms to face the problems brought about by caring with child diagnosed with paranoid schizophrenia; (3) Despite the challenges faced by the family members in caring for their children diagnosed with paranoid schizophrenia, positive attitude was a key factor in successfully managing with the problems related with taking care of children with paranoid schizophrenia.

Keywords- Lived Experiences, Family Members, Maladaptive Behavior

INTRODUCTION

Someone with schizophrenia is not capable of social functions. Hence a strong support system or group is needed in order for the patient to be a strong individual who respects himself and achieve a better level of healing and improvement to function socially. Families have an important role in the recovery of patients diagnosed with paranoid schizophrenia.

According to a study family members are significantly distressed as a result of having a family

member with schizophrenia (Addington & Martins, 2008). The family as a provider of information and directly responsible for the patient could help provide a solution of the problem by providing advice and guidance. The family must be able to help the patient in correcting unacceptable behavior. Being with the patient and monitoring his or her behavior consistently would help the patient improve gradually through feedback about the patient's behavior. The family's pattern of behavior and value system performed daily will greatly affect the values, beliefs, attitudes and behavior of the client positively. They have the basic functions such as giving love, feeling safe, feeling owned. If the family is viewed as a system, the mental disorder in a family member will interfere with any system or family circumstances. Therefore the involvements of the family members in the care of patients greatly benefit the recovery process (Cohen *et al.*, 2009)

Based on a national survey in 2007, the documented incidence of patients with schizophrenia was approximately 1.9 % in the province of Bengkulu, Indonesia. (Department of Health of Republic Indonesia, 2013). My work as a faculty member of the Department of Psychiatric Nursing in the School of Health Sciences of Tri Mandiri Sakti in Indonesia and a clinical instructor at a Psychiatric Hospital at Bengkulu Province, I had access to the medical records of the patients with psychiatric disorder. Browsing through the said medical records dated October 2013, I have gathered that there were approximately sixty one (61) patients with psychiatric disorder like schizophrenia. The growing number of patients with schizophrenia and their alarming conditions encouraged researcher to pursue the study.

LITERATURE REVIEW

As noted, families have often been blamed for the problems of individuals with schizophrenia. It is no wonder that some families are suspicious of professionals who might view the family as the villain, nor is it any wonder that many of these families have little desire to be studied. Although research has substantiated the state of turmoil in these families, many clinicians argue that dysfunctional families are not the cause of schizophrenia but, rather, the result of having a family member with this illness. Nevertheless, once a family becomes destabilized, there is a high probability that the dysfunctional family will have a negative effect on the schizophrenic member (Ghosh & Greenberg, 2009).

Individuals with schizophrenia can be a disruptive influence on the family, particularly when they are noncompliant with prescribed medications or when they use mind-altering drugs. Although there is a consensus that negative features (e.g., emotionally over-involved, hostile, critical) are present in many families of schizophrenic patients, it should be noted that these families are studied after schizophrenia has been identified-years after the family might have been disrupted by the illness. This observation leads to the chicken or egg question raised previously: do disruptive families cause individuals to have schizophrenia, or do individuals with schizophrenia cause families to become disruptive? Although blame might be warranted in some family situations, in most cases it is not. Blaming the family leads to a sense of alienation between the family and treatment team. Nurses should remember that families bear the brunt of care outside the hospital. Most discharged psychiatric patients are sent home to live with their families; therefore, the family's stake in the patient's care is obvious. As time goes on, these families tend to become more and more isolated and feel more and more frustrated, helpless, and hopeless, even though they care very much about the patient (Keltner, 2011)

Patients with schizophrenia, besides having a clinical symptomatology, suffer from high financial and social costs which are both generated by the high costs of treatment (hospitalization and emergency interventions) and by the associated social stigma. In addition, schizophrenia is commonly identified by people as "mental disorder" and is considered by the community as the most serious condition (Shives, 2008).

Schizophrenia does not only affect patients, but it also constitutes a considerable burden to their families. When a person develops schizophrenia, parents usually experience feelings of anger and anxiety, guilt, fear,

frustration and sadness which should be considered as an integral part of treatment of the patients and their families. Furthermore, the burden of taking care of a patient with schizophrenia is associated with quality of life reduction and a significant impact on the health and behavior of the family. As a consequence of this experience relatives use different coping strategies as mechanism to decrease anguish (Foldemo, Christina & Bogren, 2007)

Families of people with persistent mental disorders have special needs. Many of these adults continue to live with their parents well into their 30s and 40s. In case of adults with persistent mental illness, the family serves several functions, for those without mental illness do not need any such help. Such functions include the following: (1) *Providing support*. People with mental illness have difficulty maintaining outside or non-familial support networks and may rely exclusively on their families. (2) *Providing information*. Families often have complete and continuous information about care and treatment over the years. (3) *Monitoring services*. Families observe the progress of their relative and report concerns to those in charge of care. (4) *Advocating for services*. Family groups advocate for money for residential care services (Seloilwe, 2007).

Few families have had experience with mental illness to help them deal with the manifestations of schizophrenia. The initial episodes are often accompanied by mixed emotions of disbelief, shock, fear, and concern for the family member. Maybe these are isolated or transient episode that are also present. Families initially may seek reasons, attributing the episode to taking illicit drugs or to extraordinary stress or fatigue. They do not know how to comfort their disturbed family member and may find themselves fearful of his or her behaviors. The patient is hostile and aggressive toward family members, the family may respond with anger and hostility along with fear, confusion, and anxiety. During these episodes, some families seek help from police to help control the situation (Fortinash & Worret, 2007).

The initial period of illness for a patient and family who receive a diagnosis of schizophrenia is extraordinarily difficult. Families may deny the severity and chronicity of the illness, engage in the activities of their previous lifestyle, and only partially engage in treatment within the mental health system. Often, during the initial phase of treatment, explanation and education about illness may be minimal. As families acknowledge the severity of the diagnosis and the long term care and extensive rehabilitation required, they may feel overwhelmed, angry, and depressed (Boyd, 2008).

METHODOLOGY

The study utilized a qualitative phenomenological approach in exploring the lived experiences of family members with children with maladaptive behavior diagnosed with paranoid schizophrenia. Qualitative research is a broad term used to describe research that is focused primarily on human experience through exploring attitudes, beliefs, values, and experiences (Whitehead, 2007).

RESULT

1. Two interrelated themes emerged in the researcher's exploration to the 10 of family members who have children with maladaptive behavior from 61 people of family members. The first theme is **encountered challenges**; were experiences brought by problems and difficulties faced by family members. The second theme that emerged from the lived experiences of family members with children diagnosed with paranoid schizophrenia is **coping**; a positive reappraisal or cognitive process whereby a person focuses on the good in what is happening or has happened.

2. The challenges encountered by family members are social stigma, emotional and social difficulties (feelings of being ashamed, stressful condition, anxiety, worry, sadness and burden in life).

3. Coping of family members included several support mechanisms, spiritual approach, support groups, available alternatives, optimism, positive outlook in life, and love of parents.

Table 1: Summary of Meanings, cluster of themes, sub themes, and themes

Verbal Transcriptions	Meanings	Cluster of Themes	Sub themes		Main Themes
"You know, I felt ashamed towards my friends and neighbors. I felt very, very ashamed.It wouldn't be a problem if it was only rambling but it was more than a rambling!"	There is a shameful feeling among family members for having a child with mental disorder. Worries are more of being alienated by friends and neighbors and even in the society at large.	Feeling ashamed towards friends and neighbors	Social stigma	1. Social stigma 2. Emotional difficulties and social difficulties *(Being ashamed, stressful condition, anxiety, worry, sadness and burden in life)*	Challenges encountered
"Yes, I am ashamed. I always said, "Oh God, how come my family is like this while other people are normal".	Comparison of mental health condition with others. There is a feeling of insecurity due to the different mental condition of a family member leading to embarrassment.	Feeling ashamed			
"Upon knowing that my child has this mental disorder, I got so discouraged, I was ashamed but now after ten years it does not affect me anymore. I considered having a child who has this mental disorder as my fate, a test from God and I accept it".	There is discouragement at the initial stage of knowing the mental condition of their children but family members have accepted it and lived with the fact and have outgrown the feeling of discouragement.	Feeling ashamed the first time they learned of the mental health condition of their children.			
"Of course it affected me. I felt anxious, restless, irritated..."	Due to the societal stigma of a mental illness, family members suffers emotionally as well.	Feeling of anxiety, restlessness, and irritation.	Emotiona l and Social difficulties		
"Yes, surely it affected my physical and mental hea lth being so disturbed. There is not a single time that I he is not in my mind. I am always worried and stressed because I fear that his maladaptive behavior would result to an unpleasant result."	Family members are affected physically, psychologically and emotionally by the mental condition suffered by somebody in the family. One of the causes of such is their disturbing behavior that affects other people outside the family.	Physical and mental effect on the family members			
"Actually it became a burde n to my mind and I was sad. I asked why his fate became like that? When I am very sad I would feel dizzy, sometimes hypertensive, stressed and anxious often with the question in my mind why this condition happened to my family."	Family members are also affected by the mental illness suffered by their children. Whether it's physical or mental reasons.	Stressfulness and feeling of anxiety			
"It affected me physically because I had high blood pressure, so I often got dizzy, looked at him (patient) and how much effect it has affected the family also, yeah… there was also a feeling of anxiety, because of his behavior, like damaging the surrounding environment."	The mental condition of a family member affects the health of family members without the same condition. There is a feeling of unbelief at the fate of the patient and the family as well. The disturbing and uncontrollable behavior of the patient poses damage to the immediate environment.	Physical effect and anxiety			

"Yes, influence, a little dizzy, I was so busy, right? Must visit to the Psychiatric hospital, if not visited, maybe he is angry with me, sometimes dizziness, sometimes anxiety, headache, a burden to me."	The constraints of having to give priority to the treatment of the patient at home and at the hospital affects the family members.	Anxiety, headache
"What I need is that the psychiatric hospital can guide him, the patient, to get completely cured, and for the hospital to provide guidance on how to put him in control when he is dischar ged to the house. In addition, for us to be given a guarantee that the patient gets a free medical service, because it becomes an economic burden to us."	There is a feeling of inadequacy to meet the psychological need of their children with mental disorder to recover fast. It is in this context that they suggest that the hospital provide them knowledge on how to better care for their children as well as getting free medical services for the child with schizophrenia to lessen their burdens financially.	An economic burden
"Living in a family, with a mentally disordered member like this, is very, very burdensome; materially and economically and mentally. Everything is destroyed, destroyed, it's completely destroyed. So, it can be said that it is also c ausing mental disorder to me.")	There is a high financial and emotional costs involve in having a schizophrenic child.	Become a burden, burden of material/ economic, burden on mind, everything
"...so that became a burden to my mind, I felt stressed and anxious as well."	Psychological effect is evident among family members taking care of a child with mental dis order.	Become a burden of mind.
"Actually became a burden to my mind and it made me sad of his fate. Very sad, I was so dizzy, sometimes hypertensive, stressed, anxious about what is happening in my family."	There is an evidence of mental stress among family members who takes care of a child with mental disorder.	Burden to mind
"Actually, we have a family member with behavior like this. It is also a burden to us..."	Caring for children who suffer from schizophrenia affects the activities of family members. A great deal of time and physical presence is required.	Be a burden
"Because he's already forty (40) years old, I was worried about his future…"	Family members who have children with paranoid schizophrenia posed concerns about the future of their child.	Feeling worried
"I'm worried about his future… that is why if he totally recovered I want to give him the business…"	Family members who have children with paranoid schizophrenia, has showed optimism.	Worried about the future
"My concern was very big as well, so shambles family (unorganized) also, I am also concerned there are four young children, he had responsibility for his children, right?"	Family members who have children with paranoid schizophrenia stressed that there are other people in the family who are neglected because everyone is focused on the patient.	Have a big concern (Disorganized family)
"Many fears, for example, if I die who will take care for my son (crying) In addition, it such thing happen that is not desirable, who will responsible to him? I really love my son."	There is fear of who will take care of their child with schizophrenia in case the parents die.	Concerns of family members
"My concern is if the patient would not recover. At home he often disturbs the environment. My father got hit by the patient, pursued as well, he was finally put in the stockade because I was afraid he would also hit others. The people around are also afraid because he is always angry, rooms [sic] naked around the village."	The unpleasant behaviors of a child with maladaptive behavior poses a threat to the immediate community.	Fear if the patient does not recover,
"I feel worried that he (the patient) does not recover, actually I want that he can completely heal…"	There is anxiety over the possibility of the mental order to remain till the child's lifetime.	Fear if the patient does not recover.
"Feeling worried and scared, because I have a family member with mental illness like that. Although he is a member of my family he makes me scared at times because of his mental condition, right? I am scared because things are different unlike before. For example, fear of hitting us. Before he was a polite and a good son. He's like being pressured because of family conflict."	External stressor poses a threat to the response of the child with mal adaptive behavior.	Feeling worried

"Concerns or worries were always exist, very big, because when the doctor said cured, I worried if he relapsed again, just because the medicine not routine, so we have to get ready to control if the medicine is already would finish, moreover worried that he was damaged the environment, or damaged other people's homes, such as breaking glass, or hitting other people, so we are responsible for overseeing the behavior of him (the patient), to prevent does not arise bad behavior."	Relapses of the patient ends the family members' hope of cure.	Feeling worried
"I am afraid that the patient may disturb others and also worried that others may underestimate him."	Due to maladaptive behaviors caused by their children, they cannot be completely trusted	Fear if the patient disturbs others
("My concern was I am afraid that if he has relapse again.")	Family members know that their child's illness at risk for relapse.	Fear if the patient relapses
"I felt sad because it affected the environment of our family life. I had to put him in a stockade due to his disturbing behavior that was affecting the neighborhood. I felt there was no other way. It's what I thought was best to do at that time thinking it's because of the devil that entered his body influencing his thoughts."	Family life changed due to the destructive behavior of the child with mental disorder.	Feeling the sadness
"I felt sad (crying), because he's not having the same health condition like others and because it is almost twenty six (26) years of his sufferings from mental illness and he is not cured. To this I feel sad."	Emotional breakdown occurs at the fact that the length of time given for treatment does not guarantee permanent cure.	Feeling the sadness
"A lot of things that I felt… sad… because my son suffered from a mental illness and was treated at the psychiatric hospital. Not unexpectedly like that, because he's a good son, he was smart at school; he also can read the Holy Qur'an properly; he also can perform sholat (prayer). Really sad; what is my fault? What is my sin? What was the sin of my son? So that my son is like that; you know he has been suffering from a mental disorder for almost 5 years.")	Acceptance of the real condition of their child is an issue. There is self blame for the fate of their children with mental disorder.	Feeling the sadness
"Sad, so sad because he would recover but would have relapses. This confuses me. What should I do?"	Relapses discourages the family members. It means that they failed in some ways in taking care of their child with mental disorder.	Feeling the sadness
"Sad, really sad because if I look back from the past when he was a student, he was active and smart and he graduated from school. So, when comparing the past and today, it really hurts me that much."	Acceptance of the real condition of their child is an issue.	Feeling the sadness
"To see him like that is very sad. First, he does not like to be like that. It is a calamity to my family. He is suffering from a mental illness. So sad, right? Previously, he was normal like the others. But I do not know if that's because of fate, right? I was very sad to see all of it . I can't say anymore anything with his condition being like that."	Comparison of mental health condition with others causes insecurity due to the different mental condition of a family member leading to embarrassment and pity.	Feeling the sadness
"Sad that he is not the same like other people, really sad. You know my parents already passed away and I have a brother who has maladaptive behavior. Actually, he was diligent, kind, generous and very caring to others but he became ill like that, very sad."	Family members pities the patient with mental disorder.	Feeling the sadness

"Sad because he is unlike other people.He is still young, he has a lot to life, right? So sad, how come life became like that for him? In fact, our family has no history of mental illness."	A question about genetic origin from the family of the mental disorder was posed.	Feeling the sadness			
"I diligently perform p rayers five (5) times always asking for directions from the Lord so that my children will be healthy always. Also I am asking for the family's health and praying that hopefully there is a way out."	Spiritual gestures are performed for additional strength and hope for healing.	Faith in God	Spiritual approach	1. Spiritual approach 2. Support groups 3. Available alternative 4. Optimism 5. Good outlook in life 6. Love of parents	Coping
"I pray to God and accept whatever the circumstances are, because this is a test f rom God."	Family members surrender to the will of God. Because of the condition of their child who suffered from paranoid schizophrenia. They perceive it as a trial.	Faith in God			
"I always pray for him, hopefully he can recover quickly, by way of pray ing to God…apart from that I could not try anything."	Family members believe that the power of prayer can make their condition much better.	Faith in God			
"I received these trials, I have to be patient, I have to be obedient to Allah (God), praying five (5) times a day."	Family members believe that the power of prayer can make their condition much better.	Faith in God			
"What I can do right now is to pray for the Lord to give me patience and strength."	Family members resort to spiritual practices to ease the problem and seek healing from the Lord.	Faith in God			
"Mmm, I just pray to God for a better life of my family."	Through prayers, they believe that healing is not impossible.	Faith in God			
"The best way at this time is pray for her healing process and my patience and sincerity."	Due to the long healing process the family members draw closer to God.	Faith in God			
"During this time of suffering from mental disorder like this, I keep trying and praying so that healing will be given by God."	The power that they have, in addition to caring for their children, is faith in God.	Faith in God			
"Pray! There is no other way for me. It's hard to recover because it's mental disorder, right? So pray to God."	An assumption that there is no other way except draw closer to who can change the situation.	Faith in God			
"…even my friends and my neighbors care for my family."	Support from friends is a big encouragement.	Neighbors care for the family members	Support groups		
"…instead, the neighbo rs encourage me to go on and be patient, it's simply a trial, but everything that happened is God's will. It is therefore impossible that a situation like that will stay unsolved forever." So I did not feel affected by his condition of him, like that. It's okay!"	Support from friends and neighbors are a big encouragement.	Neighbors support family members			
"...because the community or the environment also understands circumstances like those, right? Therefore there is no reason for the family to feel ashamed…"	Support system alleviates insecurity.	The community understands circum stances			
"I think I was not affected. As usual, I hang out with my friends and neighbors.They are kind to me, so there is not much effect having a family member who has mental disorder…"	When friends and neighbors understand there is a tendency for family members not to get affected by the situation.	Neighbors are so kind to family members			
"I made every effort to find solutions to the problems so that my son can recover by way of looking after him and keeping him because it is my obligation. We visit the Psychiatric hospital three times a week to keep up and often, I also take him to a shaman, a traditional healer hoping that it would help in his recovery but it did not have any effect. I will try anything to make his condition better."	Many efforts were made by family members to solve the problems, because they have the expectation that their children can recover.	Make every effort to find solutions	Available alternative		

"During this time I have considered and tried some alternative solutions. Much effort were exerted, a lot of money was spent unfortunately there were no positive results until finally I took him to a psychiatric hospital. We visit him there interchangeably because we are a large family."	Alternative solutions were used to find cure.	Try to look for alternative solution		
"Actually, I have given maximum effort so he can get cured. His mental illness exists for almost two (2) years already. I have tried to get treatment from the "Ulu". You know "Ulu" right? A kind of traditional medicine. After that went to the doctor, he was admitted to the Psychiatric hospital many times. In fact, we gave the maximum effort when he (the patient) was treated at the Psychiatric hospital. I was the one who monitored and provided all his needs like f ood, snacks and everything. Those were my responsibilities.")	Family members are working hard to overcome the problems encountered. A great deal of sacrifice is required in this kind of condition in the family.	Try to look for alternative solution		
"Anyway, I expect the Psychiatric Hospital to take care of him until he is healed. If he has not yet fully recovered he should not be discharged."	Family members expect the hospital to take care of their patients until healed.	Expectation from the Psychiatric hospital for order in caring	Optimis m	
"…I have very big expectations, the quick recovery of the patient and when he recovers he can help take care of the family…"	Family members desire that their children be productive in life.	Family members have very big expectations		
"My hope in taking care of him (the patient), hopefully is for my brother to recover as soon as possible…"	There is always hope for cure.	Hope of family members		
"Anyway, I hope that he can be healthy, completely recovered, can join the community again as usual and I hope people can also accept him."	Optimistic attitude of the family members.	Hope for recovery		
"…maybe he wants to get married, right? When he recover and while I am able, I want to find a woman for him to marry and I will find a job for him."	Parents wish a normal life for their children with mental disorder in the future.	Expectations for their children to get married		
"… if he recovers totally, I want to give him the business, making a lot of money, so he can have a busy and productive life."	Family members plan for the future of the patient when healed.	Expectations for their children for business	Good outlook in life	
"…Before I die, I want to see him get married, that's my biggest hope.")		Expectations for their children to get married		
"Actually, I want him to be completely healed sohe can do some activity like working and getting married, just like that."	Family members wish their children could have a normal life like everyone else.	Expectations for their children to find a job, and get married		
"*…I would do everything for him even though I am sick because I really want him to recover. I love him very much.")*	Sacrifices would be done by family members to see the patient get better and eventually healed.	Love to their children	Love of parents	
"…If I die who will care for my son? Who will be responsible for him? I really love my son."	There is great fear for the future of the patient when the parents die.	Love to their children		
"… I really love him that I never fail to visit him at the Psychiatric hospital to bring food, motivate him so he could be high in spirit and to get well soon."	Efforts of the family members to ensure a positive result on the patient.	Love to their children		

"I always facilitated what he needed. I personally feed him, make him take his medicine, make him take a bath as well. it's like that always. I really love him, hopefully he gets well soon.")	All of the needs of the patient with mental disorder are provided for by the family.	Facilitate for everything, Love to their children		
"... can recover as before, I love him, I want him healthy as usual."	Feelings of great love for their child, even though they're sick. Great sacrifice, Hoping their child would recover.	Love their children		
"...I believe that he could recover. I'll do my best although I have to struggle hard it is not a problem. The most important thing is his recovery. I can expect him to return home as usual."	Family members are willing to sacrifice anything to gain better result on the condition of their child with mental disorder.	Struggle hard to find solutions as expression of love to their children		

DISCUSSION

This study explored the essence of the lived experiences of family members with children with maladaptive behavior who have been diagnosed with paranoid schizophrenia in Bengkulu province, Indonesia. Based from the narration of the informants, the researcher was able to see the commonalities in their experiences as family members. Through the use of methodological interpretation inspired by Collaizi, themes were created and drawn. The analysis generated two major themes: Challenges encountered and Coping.

Theme 1: Challenges encountered

The first theme that emerged from the lived experiences of family members with children diagnosed with paranoid schizophrenia was about the challenges they encountered. Challenges encountered were experiences brought by problems and difficulties faced by family members. Families of patients diagnosed with paranoid schizophrenia faced many challenges where they lived with social stigma, emotional and social difficulties.

The participants, during the interview, expressed openness and honesty about their own feelings and conditions while living with children with maladaptive behavior. Family members expressed social stigma. It is the feeling of being ashamed brought about by their situation. Below are the actual statements of each informant on the social stigma felt by the family members triggered by the behavior of their children diagnosed with schizophrenia.

From participant # 3:

("You know, I felt ashamed towards my friends and neighbors. I felt very, very ashamed.It wouldn't be a problem If it was only rambling but it was more than a rambling!")

Another informant expressed the same feeling of social stigma the feeling of being ashamed because they compared the condition of their children with mental disorder to others who are not suffering from the same mental disorder.

From participant # 5

("Yes, I am ashamed. I always said, "Oh God, how come my family is like this while other people are normal".)

From participant # 1

Unlike the others, for this informant, the feeling of social stigma, such as being ashamed of their family's situation was deeply felt for a while but as days and moths passed by the feeling of being ashamed was overcame.

("Upon knowing that my child has this mental disorder, I got so discouraged, I was ashamed but now after ten years it does not affect me anymore. I considered having a child who has this mental disorder as my fate, a test from God and I accept it".)

The feelings expressed by the participants based on their actual statements in general clearly demonstrated that every single member of the family suffered from social stigma. Patients with schizophrenia are a challenge to the families because of the social stigma,

inadequate treatment, and with very little psychosocial support and, limited economic resources, and the draining cost of long-term therapy. These factors which often lead to feelings of shame and boredom to the family as caregivers. Kristoffersen & Mustard (2000), identified the emotional responses that arise when siblings have a brother or sister with schizophrenia described feeling of shame, grief, and anger. Schizophrenia and mental illness in general, continue to be one of the most stigmatized of all illnesses.

According to Kadri *et al.*, (2004), stigma is the social devaluation of a person because of a personal attribute, which leads experience of shame, disgrace, and social isolation. The presence of people with schizophrenia is often perceived as a burden on families, so many families are ashamed to admit the patient as part of their family. Many of the negative consequences of schizophrenia at the individual level are often the result of the stigma associated with the disorder.

Some participants had to put up with anxiety and stress while they lived together in the house and even during treatments of their children in a psychiatric hospital. Anxiety and stress refer to the emotional responses of family members who have children with maladaptive behaviors, the assessment that described a state of unrest, discomfort, and physical problems. Below are the actual statements of each informant on their accounts on anxiety and stress felt by the family members triggered by the behavior of their children diagnosed with schizophrenia.

Participant # 1:

("Of course it affected me. I felt anxious, restless, irritated...")

Participant # 2:

("Yes, surely it affected my physical and mental health being so disturbed. There is not a single time that I he is not in my mind. I am always worried and stressed because I fear that his maladaptive behavior would result to an unpleasant result").

Participant # 7:

("Actually it became a burden to my mind and I was sad. I asked why his fate became like that? When I am very sad I would feel dizzy, sometimes hypertensive, stressed and anxious often with the question in my mind why this condition happened to my family.")

Participant # 8:

("It affected me physically because I had high blood pressure, so I often got dizzy, looked at him (patient) and how much effect it has affected the family also, yeah... there was also a feeling of anxiety, because of his behavior, like damaging the surrounding environment.")

Participant # 9:

("Yes, influence, a little dizzy, I was so busy, right? Must visit to the Psychiatric hospital, if not visited, maybe he is angry with me, sometimes dizziness, sometimes anxiety, headache, a burden to me.")

Problems that are often experienced by family members while looking after their children suffering from paranoid schizophrenia are burdens. The cost required for the patient's treatment and the emotional effects to the family makes daily engagements and relationships unstable and has a great effect on functioning as one family.

According to Friedrich, Lively & Rubenstein (2008), schizophrenia is a devastating illness not only for the person who is ill but also for the entire family. Accordingly, the most vulnerable and most affected are the siblings. As a consequence of unremitting stress, multiple aspects of their lives are affected including relationships, roles, and health. Stress is a fact of life known to everyone. Humans deal with it in varying forms and degrees on daily basis. Seyle defined stress as the nonspecific response of the body to any demand regardless of its nature. It is a state produced by a change in the environment that is perceived as challenging, threatening or damaging to a person's dynamic balance or equilibrium (Boyd, 2008).

Some participants suffered from emotional and social difficulties that are burdensome on their lives. Burden of life is a psychological state that ensues from the combination of the physical work, emotional and social pressure, like the economic restriction that arise of taking care of the patients. According to Alejandra *et al.*, (2012), schizophrenia not only affects the patients but also constitutes a considerable burden for their families. The family suffers from high financial and social costs which are generated by the high costs of treatment (hospitalization and emergency interventions) and by the associated social stigma. Furthermore, the burden of taking care of a patient with schizophrenia is associated with quality of life reduction and a significant impact on

the health and behavior of the family. Below are the participants are the actual account of their feelings:

Participant # 2:

("What I need is that the psychiatric hospital can guide him, the patient, to get completely cured, and for the hospital to provide guidance on how to put him in control when he is discharged to the house. In addition, for us to be given a guarantee that the patient gets a free medical service, because it becomes an economic burden to us.")

Participant # 3:

("Living in a family, with a mentally disordered member like this, is very, very burdensome; materially and economically and mentally. Everything is destroyed, destroyed, it's completely destroyed. So, it can be said that it is also causing mental disorder to me.")

Participant # 4:

("..so that became a burden to my mind, I felt stressed and anxious as well.")

Participant # 5:

("Yes of course, it is a burden to the mind, an economic burden as well. I often have headache, anxiety and hypertension. It affected my physically and mentally.")

Participant # 7:

("Actually became a burden to my mind and it made me sad of his fate. Very sad, I was so dizzy, sometimes hypertensive, stressed, anxious about what is happening in my family.")

Participant # 8:

("Actually, we have a family member with behavior like this. It is also a burden to us...")

From the the interview, it can be said that the majority of the participant complained of the burden of having children diagnosed with paranoid schizophrenia.

According to Caqueo-Urízar, Gutiérrez-Maldonado & Miranda-Castillo (2009), burden of life is a psychological state that ensues from the combination of the physical work, emotional and social pressure, like the economic restriction that arose of taking care of the patients. The burdens of caring for a person with schizophrenia are associated with reduced quality of life and significant impacts on the health and functioning of caregivers. When caregivers appraise these objective demands as exceeding their coping abilities, subjective burden and emotional distress or discomforts are experienced. Distress and dissatisfaction are also elicited by perceived losses, both in their own life (e.g. lost opportunities because of caring for the patient) and through empathy with the patient. The care giving stressors operates within the total context of environmental stressors experienced by the caregiver, including stigma concerning schizophrenia, financial problems and other family issues.

In addition, family members who have children diagnosed with paranoid schizophrenia also experienced emotional and social difficulties like feeling worried. It was a negative experience felt by family members due to the nature of their problem. Below are the participants' actual accounts of their feelings:

Participant # 1:

("Because he's already forty (40) years old, I was worried about his future…")

Participant # 2:

("I worried about his future… that is why if he totally recovered I want to give him the business…"

Participant # 3:

("My concern was very big as well, so shambles family (unorganized) also, I am also concerned there are four young children, he had responsibility for his children, right?")

Participant # 4:

("Many fears, for example, if I die who will take care for my son (crying) In addition, it such thing happen that is not desirable, who will responsible to him? I really love my son.")

Participant # 5:

("My concern is if the patient would not recover. At home he often disturbs the environment. My father got hit by the patient, pursued as well, he was finally put in the stockade because I was afraid he would also hit others. The people around are also afraid because he is always angry, rooms [sic] naked around the village.")

Participant # 6:

("I feel worried that he (the patient) does not recover, actually I want that he can completely heal…")

Participant # 7:

("Feeling worried and scared, because I have a family member with mental illness like that. Although he is a member of my family he makes me scared at times because of his mental condition, right? I am scared because things are different unlike before. For example, fear of hitting us. Before he was a polite and a good son. He's like being pressured because of family conflict.")

Participant # 8:

("Concerns or worries were always exist, very big, because when the doctor said cured, I worried if he relapsed again, just because the medicine not routine, so we have to get ready to control if the medicine is already would finish, moreover worried that he was damaged the environment, or damaged other people's homes, such as breaking glass, or hitting other people, so we are responsible for overseeing the behavior of him (the patient), to prevent does not arise bad behavior")

Participant # 9:

("I am afraid that the patient may disturb others and also worried that others may underestimated him.")

Participant # 10:

("My concern was I am afraid that if he has relapse again")

From the results of interviews, each family member expressed different experiences being with the patient diagnosed with schizophrenia during their stay together at home and at the psychiatric hospital for the patient's treatment.

According to Solomon & Draine (1995) family members with schizophrenic patient exhibited significant higher levels of worry, helplessness, sadness and pity.

Another feeling of emotional difficulty that arose was sadness. Nine (9) out of ten (10) respondents expressed feeling of sadness. Below are the participants' actual accounts of their feelings:

Participant # 1:

("I felt sad because it affected the environment of our family life. I had to put him in a stockade due to his disturbing behavior that was affecting the neighborhood. I felt there was no other way. It's what I thought was best to do at that time thinking it's because of the devil that entered his body influencing his thoughts.")

Participant # 2:

("I felt sad (crying), because he's not having the same health condition like others and because it is almost twenty six (26) years of his sufferings from mental illness and he is not cured. To this I feel sad.")

Participant # 3:

("Because I got a test from God like this, I felt sad, very sad. I was not able to talk anymore, it's really sad. Why did he have a different fate? Why do I have a family member with mental disorder? I want my brother, the patient to be like other normal people, right? All of them are healthy. How come my family member is sick like this? You know I am really sad.")

Participant # 4:

("A lot of things that I felt… sad… because my son suffered from a mental illness and was treated at the psychiatric hospital. Not unexpectedly like that, because he's a good son, he was smart at school; he also can read the Holy Qur'an properly; he also can perform sholat (prayer). Really sad; what is my fault? What is my sin? What was the sin of my son? So that my son is like that; you know he has been suffering from a mental disorder for almost 5 years.")

Participant # 5:

("Sad, so sad because he would recover but would have relapses. This confuses me. What should I do?")

Participant # 6:

("Sad, really sad because if I look back from the past when he was a student, he was active and smart and he graduated from school. So, when comparing the past and today, it really hurts me that much.")

Participant # 7:

("To see him like that is very sad. First, he does not

like to be like that. It is a calamity to my family. He is suffering from a mental illness. So sad, right? Previously, he was normal like the others. But I do not know if that's because of fate, right? I was very sad to see all of it. I can't say anymore anything with his condition being like that.")

Participant # 9:

("Sad that he is not the same like other people, really sad. You know my parents already passed away and I have a brother who has maladaptive behavior. Actually, he was diligent, kind, generous and very caring to others but he became ill like that, very sad.")

Participant # 10:

("Sad because he is unlike other people.He is still young, he has a lot to life, right? So sad, how come life became like that for him? In fact, our family has no history of mental illness.")

The statements of the participants above about how they felt having children with maladaptive behavior showed that families generally feel the same sadness. Some of the factors of their feeling of sadness are due to: (1) absence of mental illness in their family's history; (2) a comparison of the patient's mental condition to; (3) the tedious task of treatment and the length of time involved of the healing process; (4) the effects of the situation in their own personal life and their immediate environment.

Foldemo, Christina & Bogren (2012), pointed out that when a person develops schizophrenia, parents usually experience feelings of sadness, anger, anxiety, guilt, fear, and frustration which should be considered in the integrative treatment of the patients and their families. Furthermore, the burden of taking care of a patient with schizophrenia is associated with quality of life reduction and a significant impact on the health and behavior of the family. As a consequence of this experience, relatives use different coping strategies as mechanism to decrease anguish.

Theme 2: Coping

The second theme that emerged from the lived experiences of family members with children diagnosed with paranoid schizophrenia is coping. The theme "coping" for the participants included several support mechanisms such as emotional, social, and spiritual aspects of support.

According to Stalberg, Ekerwald & Hultman (2004), coping is as constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing. Coping is a positive reappraisal or cognitive process whereby a person focuses on the good in what is happening or has happened. It is also a behavioral tool which may be used by individual to compensate or overcome adversity, disadvantage or disability of the underlying adaptive coping strategies to solve the problem that is causing the anxiety so the anxiety is decreased (Keltner, 2011).

There are two general types of coping strategies identified namely problem-solving strategies that are efforts to do something to alleviate stressful circumstances while emotion-focused coping strategies involve efforts to regulate emotional consequences of stressful or potentially stressful events. In the research by Folkman & Lazarus, (1986), people used both types of strategies to combat most stressful events. As to its predominance, one strategy over the other is determined depending on the personal style of the individual.

Effective coping is very important to solve the problems faced by family members who have children with maladaptive behaviors. When families face problems by utilizing the resources then they will be free from the stress and reduce the negative impacts, resource family coping is the power of the individual and collective strengths when faced adversities with a stressor as a cause of stress. Siblings should know how to cope with schizophrenia and its impact on their lives. Although the burden is costly for siblings, minimal attention has been paid to coping positive and mental health services that could reduce the stress they experience.

The theme of "Coping" is how family members cope with their challenges, problems, and difficulties lived with children with diagnosed paranoid schizophrenia, the participants describe sources of support and concern that gave them the encouragement, strength, hope and motivation to overcome the struggles and challenges of family members.

Based on the interviews on the ten respondents, each family member has a generally common spiritual approach. Praying to God for the healing of their patients. Here are the statements of the participants on how they addressed the problems spiritually:

Participant # 1:

("I diligently perform prayers five (5) times always asking for directions from the Lord so that my children will be healthy always. Also I am asking for the family's health and praying that hopefully there is a way out.")

Participant # 2:

("I pray to God and accept whatever the circumstances are, because this is a test from God.")

Participant # 3:

("I always pray for him, hopefully he can recover quickly, by way of prayer, pray to God…apart from that I could not try anything")

Participant # 4:

("I received these trials, I have to be patient, I have to be obedient to Allah (God), praying five (5) times a day.")

Participant # 5:

("What I can do right now is to pray for the Lord to give me patience and strength.")

Participant # 6:

("Mmm, I just pray to God for a better life of my family.")

Participant # 7:

("The best way at this time is pray for her healing process and my patience and sincerity.")

Participant # 8:

("During this time of suffering from mental disorder like this, I keep trying and praying so that healing will be given by God.")

Participant # 10:

("Pray! There is no other way for me. It's hard to recover because it's mental disorder, right? So pray to God.")

Another informant said different things to overcome challenges and problems encountered in having a child with maladaptive behavior. According to participant # 9:

"As usual, I like to divert my attention to my work so I won't get stressed. I have to be patient as well.")

In a study done by Henning (2011), established that "faith plays an important role in establishing a sense of meaning necessary for coping with life's stressors and traumas. Faith influences almost everything in our life. Our principles and morals depend on faith but also our understanding and maturity as well. Religious individuals are frequently motivated to conserve or protect their foundational beliefs or cores of fundamental spirituality. The study concluded that the usefulness of an individual's religious commitment is dependent on the current maturity level and their commitment to the faith itself. In addition to this, faith must first be developed and strengthened before using it as a useful coping strategy.

In addition, coping to overcome the problems should come from support groups. Some members of the family are having a positive experience because of the support coming from friends, neighbors and others. This support lightens up their burden of the daily emotional and social necessities required of them from having a schizophrenic family member.

According to Orford (1994), a form of behavior that fosters comfortable feeling and make people believe that individuals are respected, valued, loved and others are willing to provide care and security. Here are the statements of the participants on feeling of comfort:

Participant # 2:

("…even my friends and my neighbors care for my family.")

Participant # 7:

("…instead, the neighbors encourage me to go on and be patient, it's simply a trial, but everything that happened is God's will. It is therefore impossible that a situation like that will stay unsolved forever." So I did not feel affected by his condition of him, like that. It's okay!")

Participant # 8:

("…because the community or the environment also understands circumstances like those, right? Therefore there is no reason for the family to feel ashamed…")

Participant # 10:

("I think I was not affected. As usual, I hang out with my friends and neighbors.They are kind to me, so there is not much effect having a family member who has mental disorder…")

Based on the participants statements above, it showed that support from others helped them face their struggles related to having a child with maladaptive behavior.

According to Videbeck (2016), social support systems can be helpful in emphasizing the strengths of individuals and families and in focusing on health rather than illness. This support is important for all levels of prevention-primary, secondary, and tertiary and it influences all of the following: (1) encouraging health promotion behavior; (2) helping people seek assistance earlier; (3) improving the functioning of the immune system or other biological processes; (4) reducing the occurrence of potentially stressful events; (5) fostering the ability to cope with stressful events; and (6) helping one to deal with chronic mental and physical illness.

Some participants exerted great effort to cope and adjust to the challenges or problems that they faced by using available alternative ways. Various efforts carried out by family members like providing daily needs of their children is an alternative treatment. This condition shows that they have a positive attitude; focusing on the solution in caring for their children with maladaptive behaviors. Here are positive efforts as experienced by the participants while caring for their children:

Participant # 1:

("I made every effort to find solutions to the problems so that my son can recover by way of looking after him and keeping him because it is my obligation. We visit the Psychiatric hospital three times a week to keep up and often, I also take him to a shaman, a traditional healer hoping that it would help in his recovery but it did not have any effect. I will try anything to make his condition better.")

Participant # 3:

("During this time I have considered and tried some alternative solutions. Much effort were exerted, a lot of money was spent unfortunately there were no positive results until finally I took him to a psychiatric hospital. We visit him there interchangeably because we are a large family.")

Participant # 7:

("Actually, I have given maximum effort so he can get cured. His mental illness exists for almost two (2) years already. I have tried to get treatment from the "Ulu". You know "Ulu" right? A kind of traditional medicine. After that went to the doctor, he was admitted to the Psychiatric hospital many times. In fact, we gave the maximum effort when he (the patient) was treated at the Psychiatric hospital. I was the one who monitored and provided all his needs like food, snacks and everything. Those were my responsibilities.")

Based on the above statements, the participants indicated finding other solutions for the betterment if not cure for their patient. Alternative treatments were commonly resorted to by the participants. This type of coping strategy focuses on solving the problems to eliminate the cause of the disease and somehow eliminate their own personal stress.

Optimism of the participants that their children would heal is a factor in finding solution to their problem. Optimism refers to the basic form of the belief in something that is desired and that will be obtained or an event will lead to goodness in the future (Boyd, 2008).

Despite the length of time for recovery, healing and even treatment, family members taking care of their children with maladaptive disorder keep positive expectations. Being optimistic for a better condition for their children becomes a daily attitude. Here are some statements from the participants about their positive expectations despite their children's mental condition:

Participant # 2:

("Anyway, I expect the Psychiatric Hospital to take care of him until he is healed. If he has not yet fully recovered he should not be discharged.")

Participant # 3:

("...I have very big expectations, the quick recovery of the patient and when he recovers he can help take care of the family…")

Participant # 9:

("My hope in taking care of him (the patient), hopefully is for my brother to recover as soon as possible…")

Participant # 10:

("Anyway, I hope that he can be healthy, completely recovered, can join the community again as usual and I hope people can also accept him.")

Based on the above participants' statements, their expectations on their patients' recovery is very positive. They look forward to the future where everything is changed where their children is healed or have recovered and are functioning normally again.

Family members also have good outlook of life. They want that their children to function normally as a member of the family, as a person in the society, getting married and working for the family. Good outlook in life refers to the participants' desire for a positive change on their problematic condition brought about by having children with mental disorder. This is a proof that family members would like the care and concern from others. They expect that psychiatric hospital can give attention to the family of the patient as well not only to the patient. According to them:

Participant # 1:

("...maybe he wants to get married, right? When he recover and while I am able, I want to find a woman for him to marry and I will find a job for him.")

Participant # 2:

("... if he recovers totally, I want to give him the business, making a lot of money, so he can have a busy and productive life.")

Participant # 4:

("...Before I die, I want to see him get married, that's my biggest hope.")

Participant # 6:

("Actually, I want him to be completely healed sohe can do some activity like working and getting married, just like that.")

Desire is extremely important in life, for it allows them, compels them to work towards something better for themselves and others. If they desire a better life for themselves and their family, they are going to work towards that better life.

Love is another source of coping. The affection or the love coming from their parents refers to the positive attitude towards their children with schizophrenia. As the family is viewed as a system, the mental disorder in a family member will interfere with any system or family circumstances.

According to Boyd (2008), family has an important roles in the recovery of patients. They, as a provider of information and responsibilities to the patient, including providing a solution of the problem, provide advice, guidance, suggestions or feedback about what is done by the patient. Family has the basic functions such as giving love, feeling safe and feeling owned.

Below are some of the participants statements on how they show this:

Participant #1:

("...I would do everything for him even though I am sick because I really want him to recover. I love him very much.")

Participant # 4:

("...If I die who will care for my son? Who will be responsible for him? I really love my son.")

Participant # 5:

("... I really love him that I never fail to visit him at the Psychiatric hospital to bring food, motivate him so he could be high in spirit and to get well soon.")

Participant # 6:

("I always facilitated what he needed. I personally feed him, make him take his medicine, make him take a bath as well. it's like that always. I really love him, hopefully he gets well soon.")

Participant # 7:

("...can recover as before, I love him, I want him healthy as usual")

Participant # 9:

("...I believe that he could recover. I'll do my best although I have to struggle hard it is not a problem. The most important thing is his recovery. I can expect him to return home as usual.")

The statements above by the family members indicated they have less schizophrenic or mental illness. According to Walsh (2003), love is an attitude that is expressed through empathic understanding, respect and compassion, acceptance, and therapeutic genuineness, or honesty and openness toward others. It is more personal as distinguished from therapy relationships. Love may be defined as "that which satisfies our need to receive and bestow affection and nurturance; to give and be given assurance of value, respect, acceptance, and appreciation; and to feel secure in our unity and belonging to a particular family as well as the human family." Love of parents is a positive attitude so they are a support system which can help the healing process of children with maladaptive behaviors.

CONCLUSION

The preceding findings led to the following conclusions:

1. Family members faced social stigma, emotional and social difficulties in caring for their children which leads to

experiences of feelings of being ashamed, stressful condition, anxiety, worry, sadness and burden in life.

2. In addressing the challenges, family members adopted coping mechanisms to face the problems brought about by caring with child diagnosed with paranoid schizophrenia.

3. Despite the challenges faced by the family members in caring for their children diagnosed with paranoid schizophrenia, positive attitude was a key factor in successfully managing with the problems related with taking care of children with paranoid schizophrenia.

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