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Surviving Schizophrenia in the Family: Four Case Studies

Perry Paul J. Espinosa

Assistant Professor, Department of Nursing
Woosong College, Daejeon, Republic of Korea
paulespinosa721@gmail.com

Abstract

This is a qualitative research, case study approach which explores the survival strategies of family members living with schizophrenic patients. The study consisted of a face-to-face, semi-structured interview with the twelve family members of four schizophrenics. Holloway's Strategy was used in analyzing the data. The problems and difficulties identified are illness-related, eating, sleeping, and hygienic problems. The extent of problems reported ranges from minimally to extremely disruptive to family life, however, most of them had coped effectively. Family members were emotionally involved in taking care and supportive of their schizophrenic family member.

Keywords*: Schizophrenia; Surviving schizophrenia; Living with schizophrenia; Coping schizophrenia; Family members with schizophrenia*

1. Introduction

People deal with mental illness differently. Some hide it, others whisper about it, and some even announce it publicly. Schizophrenia is a chronic and severe mental disorder that affects how a person thinks, feels, and behaves. People with schizophrenia may seem like they have lost touch with reality. Although schizophrenia is not as common as other mental disorders, the symptoms can be very disabling [2].

Schizophrenia is a disease that typically begins in early adulthood; between the ages of fifteen and twenty five. Men tend to develop schizophrenia slightly earlier than women; whereas most males become ill between sixteen and twenty five years old, most females develop symptoms several years later, and the incidence in females is noticeably higher in women after age thirty. The average age of onset is eighteen in men and twenty five in women. Schizophrenia onset is quite rare for people under ten years of age, or over forty years of age [2].

Estimates of the incidence and prevalence of schizophrenia vary by geographic area and across time wherein it has been estimated that approximately 51 million people suffer from schizophrenia worldwide. At present, there is no cure for schizophrenia [2]. The goals of treatment include the improvement of symptoms, patient rehabilitation, improved quality of life, and the prevention of relapse and re-hospitalization [7].

In some instances, however, when mental illness strikes in a family, it is devastating, like being struck by lightning. Because of society's misunderstanding of mental illness, it is often similar to the experience of some terrible humiliating event which brings shame to family members [15]. Caregivers experience a maelstrom of emotions as they struggle to understand what has happened to their loved one [11].Family responses to having a family member with schizophrenia include care burden which is moderately high level, fear, shame, and embarrassment about signs and symptoms, uncertainty about the course of the disease, physical and financial burden, lack of social support, and stigma [3,4,5,8,9,10]. These are not uncommon reactions and emotions, given the fact that the diagnosis of mental illness has carried a lot of negative associations and impact in our society.

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Many families who have a loved one with mental illness share similar experiences. One may deny the warning signs, worrying what other people will think because of the stigma, or may wonder what caused the family member to become ill [14].

Care activities for patients with schizophrenia are difficult, often long-term responsibilities of the families [6]. However, their love and support of family plays an important role in schizophrenia treatment and recovery.

Cases of schizophrenia in the Philippines are on the rise with increase in population, however, the Filipinos' faith in God and sense of humor helps them cope with situations [12]. The families who deal most successfully with schizophrenia are those that come to accept the illness and its difficulties, are realistic in what they expect of the ill person and themselves, keeping a positive outlook, and can maintain a sense of humor [1]. It was noted then that every day family members have to choose to survive mental health. Locally, studies about how the family members survived from schizophrenia are scarce. Not much is known as to how they manage and cope with the situation.

Family members have their own perspective of mental health, recovery, and survival. They have their own stories, their own struggles, and their own recovery. Learning to live with it needs time, patience, and courage. It is interesting therefore to explore their survival strategies, specifically on what strategy they use to help cope and how they survive from schizophrenia.

2. Objective of the Study

This study was conducted to describe the coping strategies and problem solving skills of four families with a schizophrenic member.

3. Significance of the Study

The results of the study are beneficial to the family members of mentally ill clients, Department of Health, Health Educators, Mental Health Nurses, Nursing Students, and Future Researchers.

The result of this study may provide valuable information to family members of mentally ill clients. Family members may better understand schizophrenia as well as the difficulties and problems associated with the illness. This would primarily help the family members in terms of more effective coping strategies. It is an accepted fact, that, mental illness in the family is a major life crisis. It alters the structure of everyday life, and the changes themselves will add distress, yet families can and do survive the experience.

This study would provide further information to the Department of Health in an effort to promote, prevent, cure, rehabilitate, and maintain mental health concerns to individuals and communities.

The result of this study would render responsibility to health educators and mental health nurses for them to collect and analyze data for the purpose of researching, designing, and presenting promotive, preventive, curative, and rehabilitative mental health care programs. The results would also provide useful insights into the challenges that mental health professionals need to address and highlight some of the changes they need to make for mental health care programs to work for both the mentally ill and family members.

This study would guide student nurses as well as equip them with the knowledge and skills on the proper way of giving health teachings and prevention programs to family members of schizophrenic clients.

The result of this study could serve as additional information to other researchers who may wish to conduct similar study.

4. Methodology

4.1 Research Design

This is a qualitative research, case study approach. Sagadin, 1991 cited by [16] states that a case study is used to analyze and to describe, for example each person individually (his or her activity, special needs, life situation, life history, etc.), a group of people (a school department, a group of students with special needs, teaching staff, etc.), individual institutions or a problem (or several problems), process, phenomenon or event in a particular institution, in detail.

4.2 The Participants

The participants of the study were the twelve family members of four schizophrenic patients. The schizophrenics were taken from the care of a private practicing psychiatrist. They were composed of two males and two females, classified into acute and chronic cases of schizophrenia. The duration in terms of the number of years diagnosed with schizophrenia, history of mental illness in the family, and the family monthly income were also considered.

4.3 Data Sources and Collection Procedure

The primary research instrument in any qualitative research is the researcher himself. Using the requirements of reflexivity, the researcher maintained its bias-free and well-guided philosophical outlook in synthesizing the collected experiences. The research utilized descriptive way of narrating their experiences, individually and thematically. Describing each detail would give the readers a comprehensible representation of the participants' life.

This research consisted of a face-to-face, semi-structured interview with each of the family members as the main source for collecting experiences. The semi-structured interview guide provides a clear set of instructions for interviewers and can provide reliable and comparable qualitative data [17]. This type of interview is often used when the researcher wants to delve deeply into a topic and to understand thoroughly the answers provided [18].

An open-ended set of questions were used as a guide in all interviews. Depth-probes were also used to elicit-rich responses. The key to successful interviewing is learning how to probe effectively, that is, to stimulate an informant to produce more information without injecting oneself so much into the interaction which could only result to reflection of oneself in the data [19].

The participants were scheduled for a home visit during day and evening hours of the week and on the weekends wherein each of the family members were visited twice, and during the first day, establishing a rapport was done to them. A minimum of one day elapsed between the first and second interviews was done to allow the researcher to refine the questioning and allow the interviewees time to reflect on possible additional insights they may have wanted to. The interview about their survival and coping strategies were done on the second day, which was lasted to one and a half to two hours.

4.4 Ethical Considerations

Ethical considerations were adequately addressed. Permission to conduct the study was obtained from the Research Adviser and Dean of the School of Graduate Studies. Before the study was conducted, the consent form was given and thoroughly explained to each participant stating the purpose of the study. They were assured of strict confidentiality throughout the study, in which any information provided by them would not be publicly

reported in a manner that would identify them as the participants of the study. Each of them was made to sign the consent form and each of them was given a copy.

Furthermore, it was explained that their participation was voluntary and that they were given the freedom to refuse and withdraw at any time whenever they feel threatened of their personal integrity. Their welfare was protected throughout the study and was treated with dignity and respect.

4.5 Ensuring Trustworthiness of the Study

To establish trustworthiness in this study, Lincoln and Guba's (1985) criteria was used in judging the soundness of qualitative research. This includes credibility, transferability, confirmability, and dependability. These were observed and followed throughout the research process.

4.6 Data Analysis

The Holloway's Strategy was used in analyzing the data. The steps are ordering and organizing the collected material, re-reading the data, breaking the material into manageable sections, identifying and highlighting meaningful phrases, building, comparing and contrasting categories, looking for consistent patterns of meanings, searching for relationships and grouping categories together, recognizing and describing patterns, themes and typologies, and interpreting and searching for meaning [13].

To begin the process of ordering and organizing the collected data, data collected were read and rewritten (family member interviews, observations, and journal notes) several times and marked information by underlining relevant words or phrases and making notes in the margins for the purpose of creating a summary of the paraphrased or marked information of each data. Next, phrases were highlighted and summary tasks were made. Then, the summary of each data were compared identifying the themes by determining similarities and patterns among them. The last step involved searching for relationships and grouping categories together, recognizing and describing patterns and themes, and interpreting and searching for meaning.

4.7 Data Gathering and Analysis Flow Chart

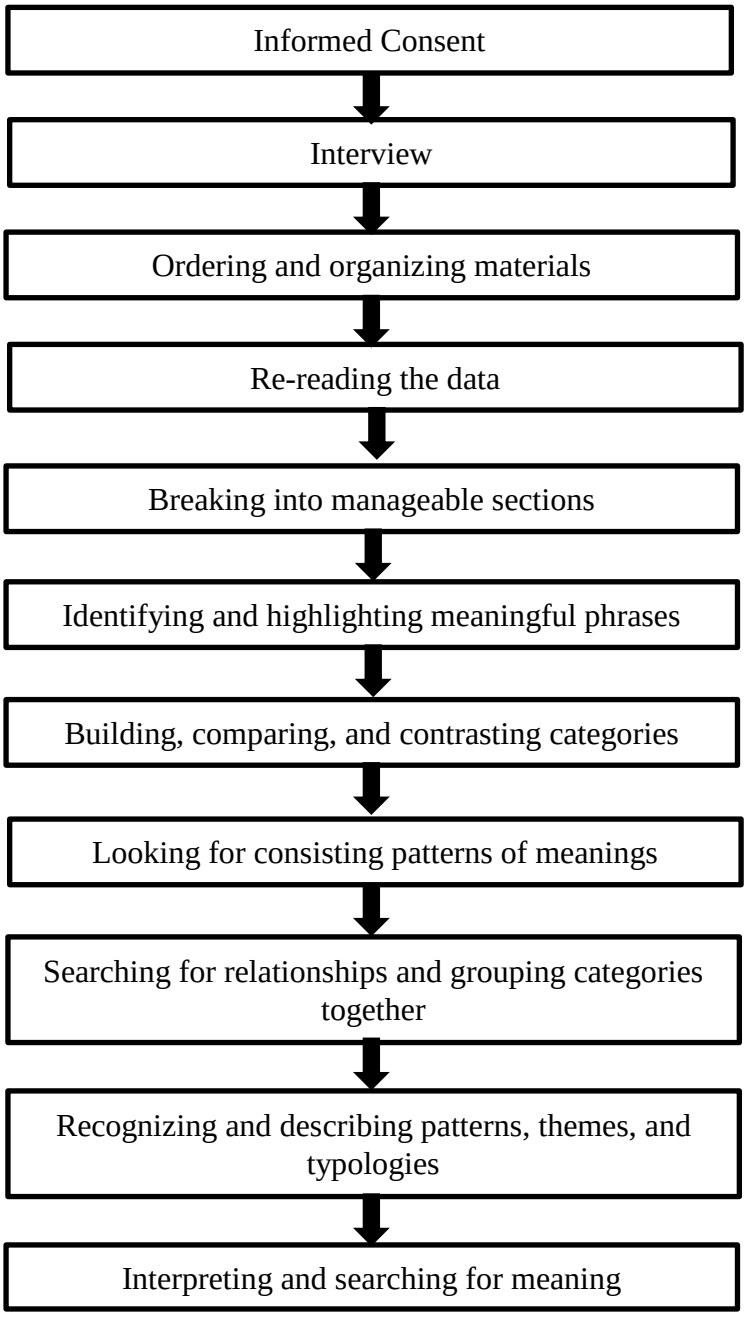

Figure 1. Flow Chart of Data Gathering Procedure and Data Analysis Plan

5. Results

The problems and difficulties identified are illness-related, eating, sleeping, and hygienic problems.

In terms of illness-related problem, all of them coped with praying, bringing the patient to the psychiatrist and hospital for further psychiatric evaluation, providing safety and support, sharing their own experiences to other members of the family and acknowledging the reality of schizophrenia.

In terms of eating problem, cooking of food upon request and bringing the schizophrenics to the restaurant were made by the family members. One of the mothers would give whatever food is available and at times would just ignore if the schizophrenic would ask for food.

Schizophrenics had difficulty initiating sleep and would sleep very little at night not longer than 3 hours. Turning on the radio, listening to music, walking outside of the house, and increasing the dosage of the medications were the strategies of the family members.

Hygienic problem was also noted to schizophrenics such as refusal in doing personal hygiene such as taking a bath, brushing of teeth, combing of hair, and changing of clothes. Strategies include talking and encouraging in doing personal hygiene and enhancing positive self-image through encouragements and gentle reminders.

The following is a vignette for one client which can represent a pattern of experience typical of cases of a family with a schizophrenic member.

S.A., a 52 year-old, male, single, and is a college graduate and belonged to the middle-class family. He was diagnosed of disorganized schizophrenia twenty years ago when he was 32 years old and has not gone back to work since he was diagnosed of schizophrenia. He is considered a chronic case of schizophrenia.

S.A. worked in a watch repair shop before he developed schizophrenia. He has not gone back to work after his diagnosis. He does not work at home, even doing the household chores. As of the moment, he could manage to take a bath by himself and can eat without assistance from the members of the family. He also watches television, roams around, and mingles with members of the family.

He is the fifth of six children of a farmer and a fulltime housewife. He has five siblings, four females and a male. The eldest is a male, who is married with three children. The second sibling is unmarried, female, a spinster, and works as a dressmaker. She is managing their small business. The third one is married, living with family. Moreover, the fourth sibling is also unmarried female, a spinster, who stays at home. The fifth among the siblings is S. A. He has a live-in partner, with whom he has two daughters. The daughters live with their maternal grandmother while S.A. lives together with his three female siblings. The youngest is unmarried female, and also a spinster.

All family members are working and have an income of ten thousand to twenty thousand pesos. The income comes from the profit in their small business as well as in the salary of each of them, however, their income is only enough for their daily needs and medications. It was also verbalized that, "the income is enough for the medications and that medications are very much needed, in order for the manifestations to be controlled".

The family has history of mental illness on the paternal side. The fourth sibling emphasized that they have history of mental illness, on the other hand, however, she cannot specify exactly the diagnosis. As noted, among themselves, four have inability to sleep especially at night. As verbalized, "aside from S.A. my second and youngest sisters have sleep problem, nervousness, and shakiness of both hands. Both of them are taking medications to induce sleep and to control the manifestations. Furthermore, I am also manifesting the same way with them, I am also taking the same medications in order to decrease nervousness."

Below are the problems and difficulties identified by the members of the family as well as their coping strategies. The problems are grouped into illness-related, hygienic, sleeping, and eating problems.

Illness-Related Problem. S.A. was noted to have negative symptoms of schizophrenia. He was noted to have blunted affect, inappropriate posture, slowed movements with low tone of voice, stays alone in the room for a long period of time, and withdraws socially from people. He was also noted to have difficulty of sleeping. With these manifestations, members of the family would bring him to psychiatrist for evaluation and management

whenever they observe these manifestations. Moreover, family members would further monitor and assist client in doing his own personal tasks such as taking a bath, changing of clothes, and eating of foods. As stated by one of the siblings, "When he is not feeling well, we monitor and assist him in doing his own personal tasks, however, every time we notice him doing inappropriately, we called up or brought him immediately to his psychiatrist". In addition, as stated, "I always pray for his recovery". "I also told him to pray, relax, and listen to music" as verbalized by the youngest sibling.

Hygienic Problem. S.A. refused to do his own personal hygiene. He would take a bath for once in a week only and does not want to brush his teeth, change his clothing, and avoid combing of hair. As verbalized by his sister, "He does not want to take a bath, he smells bad, and looks dirty. So, I always gave him twenty or fifty pesos in order for him to do own personal hygiene. Then he would usually follow". When it comes to oozing of saliva, they would usually place or tie a clean cloth to his shoulder so that he could wipe his saliva. In addition, his eldest daughter s is helping him to do personal hygiene. As verbalized, I repeatedly told and encouraged him to take a bath and change his clothes, but, if he doesn't follow, I would bring him to the toilet and sponge his whole body".

Sleeping and Eating Problems. S.A. was observed to have both sleeping and eating problems. Oftentimes, he was noted to have inability to sleep at night, however, sleeps at daytime. As stated, "During the night, there was a time that he cannot sleep especially upon lying down". "He has difficulty initiating sleep and would sleep very little".

With this problem, as verbalized by his sister, "If he cannot sleep, I cannot sleep also, so I would turn on the radio, and we listen up together to music. At times we would go out together of the house even in the wee hours of the morning in order for him to breathe fresh air which would help him relax and be able to sleep". Moreover, as recommended by his psychiatrist, they increased the dosage of his medications from one-fourth milligram to one-half tablet.

Another problem that members of the family had encountered was eating problem. Sometimes he refused to eat and was observed to have poor appetite when eating at home, however, eats a lot in restaurants. With this, "We always brought him to eat in the restaurant or wherever he wanted to. He would then eat all of the foods served for him".

Family Members' Involvement in the Care of the Client. The members of the family are helping with each other to sustain their day to day needs. Each of them is directly involved in the care of their schizophrenic brother. As verbalized, "I am responsible to buy his medications". "I also accompany him wherever he goes especially when he is scheduled for consultation with the psychiatrist". In addition, "We are also responsible to cook food for him, wash his clothes, and fix his bed".

6. Discussion

The appearance of schizophrenia in a family member is invariably a disaster to the whole family. It was noted that the extent of problems reported ranges from minimally disruptive to extremely disruptive to family life. Numerous findings showed that family members caring for a schizophrenic member experienced difficulty and uncertainty about the illness and caregiving, high level of stress, and burden [3,4,5,8,9,10].

Parents, children, and siblings feel the effects of direct involvement wherein they have learned many useful strategies that can be shared with other family members. Most of them are directly involved in the care and have shared the responsibility of the schizophrenics. It was also observed that the ways family members respond to schizophrenia vary through time. To some extent, the variation is due to changes in the manifestations of illness and the degree of occupational and social disability attached to schizophrenia. Although medications are essential for controlling symptoms, the support and understanding of family is just as necessary and absolutely irreplaceable. Family members play integral roles in the recovery, rehabilitation, and overall lives of

schizophrenic patients.

The various problems encountered by families with a schizophrenic member are very difficult to manage, however, they find ways on how to manage such problems and better cope with the situation. The ability and motivation to continue their investment in spite of the pervasive personal burden of the illness is a glowing testimony to the depths of their love and commitment.

The small number of participants and the methodology of interviewing are the limitations of the study. The quality of the interview relies on the ability and willingness of the family members to articulate perceptions and to share accounts of experiences, which are personal and confidential. These, in turn, depend on the ability of the interviewer to establish and maintain rapport with the family members.

7. Conclusion

Schizophrenia touches everyone, affecting attitudes toward self and toward life, producing symptoms in other members, altering family structure, influencing life choices, and more. Families remain emotionally involved with and supportive of their schizophrenic family member.

Conflict of Interest

No actual or any potential conflict of interest regarding the publication of this paper.

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Author

Perry Paul J. Espinosa, PhD, RN, is a Professor of Nursing in Woosong College, Daejeon, Republic of Korea. He has extensive nursing undergraduate and graduate teaching experiences. In PhD programs, he has developed and taught advanced qualitative research inquiry in nursing in University of St. La Salle, Bacolod City, Philippines. He has mentored masters and PhD students and a panel member for various thesis and projects. Recently, in July and September of 2016, he presented a research paper at the 30th CINP World Congress of Neuropsychopharmacology, which was held in Seoul, Republic of Korea and the 5th European Conference in Mental Health, in Prague, Czech Republic.