

2-13-2014

# A NARRATIVE STUDY OF THE LIVED EXPERIENCES OF FAMILY CAREGIVERS THROUGH DIFFERENT STAGES OF MENTAL ILLNESS

Reshma Kamal

Follow this and additional works at: [https://digitalrepository.unm.edu/educ\\_ifce\\_etds](https://digitalrepository.unm.edu/educ_ifce_etds)

---

## Recommended Citation

Kamal, Reshma. "A NARRATIVE STUDY OF THE LIVED EXPERIENCES OF FAMILY CAREGIVERS THROUGH DIFFERENT STAGES OF MENTAL ILLNESS." (2014). [https://digitalrepository.unm.edu/educ\\_ifce\\_etds/12](https://digitalrepository.unm.edu/educ_ifce_etds/12)

This Dissertation is brought to you for free and open access by the Education ETDs at UNM Digital Repository. It has been accepted for inclusion in Individual, Family, and Community Education ETDs by an authorized administrator of UNM Digital Repository. For more information, please contact [disc@unm.edu](mailto:disc@unm.edu).

**Reshma Kamal**

*Candidate*

---

**Counselor Education**

*Department*

---

This dissertation is approved, and it is acceptable in quality and form for publication:

*Approved by the Dissertation Committee:*

Deborah Rifenburg, Chairperson

---

Mathew Lemberger TrueLove

---

Ruth Trinidad-Galván

---

Susan Smith-Pierce

---

---

---

---

---

---

---

---

**A NARRATIVE STUDY OF THE LIVED EXPERIENCES OF FAMILY  
CAREGIVERS THROUGH DIFFERENT STAGES OF MENTAL ILLNESS**

By

**Reshma Kamal**

B.A., Romance Languages, New York University, 1987  
M.A., Counseling Psychology, Teachers' College, Columbia University, 1989  
Master's in Education, Teachers' College, Columbia University, 1990

DISSERTATION

Submitted in Partial Fulfillment of the  
Requirements for the Degree of

**Doctor of Philosophy  
Counselor Education**

The University of New Mexico  
Albuquerque, New Mexico

**December, 2013**

## **Dedication**

I dedicate this study to all the families of the mentally ill who suffer in silence bound by the ties of love for their relatives. These families are always seeking to understand and are always waiting for a cure, a happening, or something that can help alleviate the distress and burden of the relative with a mental illness. They do not call it burden; they cannot call it a burden for they do take it with love and do it willingly. For this tie they are willing to give up a part of themselves, a part of their lives so that the mentally ill relative can have a little peace. In the mentally ill person's world, things are different. Those who can see beyond the mental illness can give them their hand to hold when they have lost their footing. This study aims to look at the light in the shadows of human suffering. Knowledge gives us some power and by knowing and learning we can equip ourselves with something to understand the darkness of the experiences of the human soul.

I dedicate this study to all who helped me in my quest of understanding the human experience including my wonderful advisor Dr Deborah Rifenburg whose blind dedication for her students was the pillar of my motivation. Finally I dedicate this study to my husband, to my best friends (Adriana Balthazar and Irina Ivashkova), and to my father who believed in my quest and whose wish at the end of his life was to see me accomplish my life goals. I am deeply grateful for all and everything that enabled me to be who I am today and to be able to see life through other people's eyes for in doing so we are becoming a little more human and are contributing to the welfare of the human condition.

### **Acknowledgements**

I am grateful for the help of all my class mates who were present throughout my studies at UNM. In addition to my dear Advisor Dr. Rifeny, I had the pleasure of having Dr. Susan Smith-Pierce on my committee who opened her heart to my topic of study and gave me guidance and support. In addition, I am also grateful for the help of my other brilliant committee members Dr. Mathew Eugene Lemberger-Truelove and Dr. Ruth Trinidad-Galván who agreed to share their expert knowledge with me throughout a difficult process and gave away their precious time. I thank my wise mentor Evonne Olson who showed me the way at UNM and my cherished friend Christine Abassary whose quest for knowledge motivated my own.

To all other travelers of life, once lessons are learned, once you have walked the road less traveled, there comes a day when it all makes sense. You know who you are including my loving mother, who brought me up in a different culture and taught me to respect and love the people of the world by showing me that we are all the same, all human with our pain, sorrow, and desire to be happy, and who keeps me grounded to help me see that we can reach our goals if only we have the right love and support. Thanks to all and may your gift to me which has been your presence, illuminate the way for many.

**A NARRATIVE STUDY OF THE LIVED EXPERIENCES OF FAMILY  
CAREGIVERS THROUGH DIFFERENT STAGES OF MENTAL ILLNESS**

By

**RESHMA KAMAL**

B.A., Romance Languages, New York University, 1987  
M.A., Counseling Psychology, Teachers' College, Columbia University, 1989  
Master's in Education, Teachers' College, Columbia University, 1990  
Ph.D., Counselor Education, University of New Mexico, 2013

**ABSTRACT**

This narrative study examines life histories of family caregivers caring for a mentally ill relative dealing with either schizophrenia or bipolar disorder through different stages of the mental illness. Its goal was to enhance understanding of the lived experiences of the families in question during three different stages of the mental illness which centered on mental illness as the life- course stage (Denzin, 1989). A narrative analysis of the life histories of the main caregivers through three different stages of the mental illness was conducted. They were life before, during, and after the onset of the mental illness. Family Systems theory was used as a theoretical framework in order to understand the daily lived experiences of the family. It is well documented that families of the mentally ill suffer from stress and burden, and the stigma usually associated with mental illness. The findings suggested that each stage of the mental illness is different and that the families in question experienced different levels of burden and stress at each stage. For such families tailoring the interventions to the stage that they are going through can help providers target the areas that require most assistance at a particular stage and in the long run may help with providing

the family caregivers with a better quality of life. For the families interviewed, the stage where family caregivers experienced an added amount of burden, stress, and psychological distress was during the onset and diagnosis of the mental illness. This was mainly due to the behavioral changes of the mentally ill relative which changed family relationships and homeostasis. Recent research in both schizophrenia and bipolar disorder show that a combination of pharmacological and psychosocial treatment early in the progression of the illness prevents neurological and psychological damage. Family caregivers would benefit from interventions tailored to prevent recurrence and relapse.

*Keywords:* mental illness, impact of mental illness, stages of the mental illness, family caregivers, stress, stigma, interventions, mental health of family members, schizophrenia, and bipolar disorder, recurrence of mental illness, psychotic episodes, diagnosis.

## Table of Contents

<b>Chapter 1: Introduction .....</b>	<b>1</b>
Problem Statement .....	4
Research Purpose and Question.....	5
Significance of the Study .....	6
Conceptual or Theoretical Framework .....	9
Researcher’s Background .....	10
Definition of Terms.....	12
Summary.....	15
<b>Chapter 2: Literature Review.....</b>	<b>16</b>
Changing Perceptions about the Mentally Ill.....	16
Burden, Stress, Psychological Distress, and Stigma.....	18
Burden and stress. ....	18
Psychological distress. ....	19
Stigma. ....	20
Interventions .....	21
Family Caregivers of the Mentally Ill.....	23
Family Systems Theory Overview.....	31
Homeostasis and circular causality. ....	33
Emotional triangles. ....	34
The identified patient. ....	34
Differentiation of self.....	35
Murray Bowen’s Scale of Differentiation.....	36

Extended family.....	37
Application of Systems Theory to Family Caregivers of the Mentally Ill .....	38
Stages of Bipolar Disorder and Schizophrenia .....	40
Definition of Bipolar Disorder and its Stages.....	41
Stage 0.....	42
Stage 1.....	43
Stage 2.....	43
Stage 3.....	43
Stage 4.....	44
Definition of Schizophrenia and its Stages.....	46
Prodromal stage. ....	46
Acute stage.....	46
Residual stage. ....	46
Summary.....	48
<b>Chapter 3: Methodology.....</b>	<b>50</b>
Methodological Framework/Narrative Research.....	50
Methods of Data Collection .....	54
Life Histories. ....	54
Sample.....	55
Life history interviews .....	56
Other data.....	59
Method of Data Analysis .....	59
Limitations .....	61

Trustworthiness.....	62
Summary.....	65
<b>Chapter 4: Findings.....</b>	<b>66</b>
Emerging Themes.....	66
Description of the Cases.....	67
Chemova family.....	67
Taylor family.....	68
Duran family.....	69
Lopez family.....	70
Life before the Onset and Diagnosis of the Mental Illness.....	70
The good old days/sadness.....	71
Mentally ill relatives' good qualities and loss of potential.....	75
Synopsis of Family Systems Theory in “life before the onset and diagnosis of the mental illness”.....	79
Life during the Onset and Diagnosis of the Mental Illness.....	79
Denial and disbelief about the illness.....	80
Diagnosis and medical community/triggering event and hospitalization.....	84
Finding the right medications.....	90
Loss of balance.....	93
Family's relationship: (1) emotional health/psychological distress, and (2) odd or destructive behaviors.....	96
Emotional health/psychological distress.....	97
Odd or destructive behaviors.....	102

Synopsis of Family Systems Theory during “life during the onset and diagnosis of the mental illness” ..... 107

Life after the Onset and Diagnosis of the Mental Illness..... 109

    Relationship with society and community/embarrassment and stigma. .... 110

    Burden associated with lack of financial support. .... 113

    Coping mechanisms/strategies/gaining strength..... 116

    Worry about the future of the mentally ill relative. .... 122

Synopsis of Family Systems Theory during “life after the onset and diagnosis of the mental illness” ..... 124

Differentiation of Self and the Extended Family ..... 127

Summary ..... 137

**Chapter 5: Conclusions ..... 140**

    Implications for Future Research..... 149

**References ..... 155**

**Appendix A: Interview Protocol..... 164**

**Appendix B: Interview Questions..... 165**

## Chapter 1: Introduction

The role of the families entrusted with the task of taking care of their mentally ill relative has become increasingly important as a result of deinstitutionalization.

Deinstitutionalization refers to the movement of moving hospitalized mentally ill patients from long-term hospitalizations to community care (n.d., Merriam-Webster's online dictionary (11<sup>th</sup> Ed). This meant that patients who became stable, typically with the aid of medication, were sent home as outpatients to live in the community or with their families. Initially this movement started as a result of pharmacological and psychosocial treatments in the 1950's and in the 1960's that facilitated the movement of care for mentally ill people from institutions to the community (Krieg, 2001). With the use of new antipsychotic drugs such as Chlorpromazine known as Thorazine, patients who previously were unable to live on their own were now able to live independently in society (Krieg, 2001). Another reason for deinstitutionalization was also partly due to larger social movements in the 1960's and the 1970's such as the hippie movement and the civil rights movement (Kelly & McKenna, 2004) which encouraged the notion of individual rights and freedom. This transition was also due to many court decisions where the Supreme Court ruled that patients who were not hazardous to society and who had been institutionalized against their will had the right to be treated or discharged. This movement was greatly hastened by the enactment of the federal Medicaid and Medicare programs, which enabled many patients to support themselves financially while living in the community (Krieg, 2001). Accordingly, deinstitutionalization was a movement to respect the right of self-determination (Maslow, 1943), which dictated that people have unhindered access to what life has to offer. It was an effort to offer more

liberty to the mentally ill and an effort to offer individuals who are mentally ill the right of self-determination (Krieg, 2001).

Although one of the reasons cited for deinstitutionalization may have been the growing societal interest for valuing the rights of individuals versus the rights of society (Oliver, Huxley, Bridges., & Mohamed, 1996) other researchers (Kraus & Slavinsky, 1982) argued that legislators were concerned with the rising costs of health care and discharging patients into community care was seen as more cost effective. Some even felt that deinstitutionalization may have been one of the biggest failed attempts in twentieth century America (Torrey, 1995). In other words, although deinstitutionalization may have been initiated with the best of intentions, the results created other problems due to a lack of planning to provide the mentally ill with ample resources for alternative care (Krieg, 2001).

One of the negative outcomes of deinstitutionalization is the lack of suitable mental health policy for patients with mental illness, which is aggravated by inadequate community based-services as well as a disjointed mental health-care structure. In addition, many individuals with mental illness are unable to access suitable and opportune treatment; many have a substance abuse disorder in addition to their main disorder, and engage in criminal activities to support their drug habits. When the correct help is not available many bounce between courts, jails, and prisons. (Taylor, 2008).

One of the consequences of the impetus to move the care of individuals with mental illness from hospitals to the community is that family members are forced to assume the role of caregivers (Chang & Horrocks, 2005). Family members are usually not fully equipped to deal with the care of the mentally ill (Winefield & Harvey, 1993). More often than not, the family has no training and finds caregiving burdensome (Lefley & Johnson, 1990). A

growing number of families battle with the burden imposed by a relative's mental illness and of taking care of individuals who are no longer hospitalized. According to Ostman and Hansson (2002), the number of mentally ill individuals, who are stabilized on medications and sent home, has increased over the last four decades. Muhlbauer (2002) found that four million American families battle with this type of burden. In a postal survey of families who were the caregivers of a mentally ill relative, researchers found that the family caregiver's psychological well-being was influenced by the mentally ill person's level of behavior disturbance (Winefield & Harvey, 1993). A relationship between the amount of caretaker's distress and the level of the patient's symptoms has been found in various studies. The caretaker's distress was higher if the patient's level of symptoms was higher. Conversely, the caretaker's distress was lower when the level of the patient's symptoms was lower (Winefield & Harvey, 1993).

The unfavorable effects of the psychiatric illness on relatives, also known as caretaking burdens have been the focus of studies since the early 1950's (Ostman & Hansson, 2000). At first the focus was to determine the likelihood of discharging patients into the community; later on the focus became to refine the tasks caretaking of the mentally ill. Recently, it has been to measure burden, which occurs as a result of the caretaking in clinical routine settings and in individuals involved in caretaking responsibilities such as family members of the mentally ill. The burden that arises in the families of the mentally ill is the product of: (1) the obligation of offering long-term all inclusive care which can impact relationships with the patient and with other people in the family and (2) the emotional distress and concerns that accompanies such care (Ostman & Hansson, 2000).

Ostman and Hansson (2000) also affirm that the close relatives of a mentally ill person experience considerable levels of enduring strain, which is higher for relatives of patients living at home compared to patients who are in community-care settings. To assist the families caring for a mentally ill member, it is important to understand their roles and experiences as caregivers. To this end, I herein propose a narrative inquiry of four families who are or have been the caregivers for a relative (s) who has (have) been diagnosed with either schizophrenia or bipolar disorder.

### **Problem Statement**

Today, more than four million American families face the challenge of living with loved ones who are afflicted with severe, persistent mental illness (Muhlbauer, 2002). Yet, interventions, preventions, and the western medical model focus on the individual patient with the mental illness and ignore the family and the patient's social environment (Jubb & Shanley, 2002). Some of the burdens identified by the families include: financial responsibilities, missed days from their work, disturbance in their daily lives, constraint in their social and leisure activities, and diminished attention to other family members (Dyck, Short, & Vitaliano, 1999). Such families feel the burden because they may be conflicted about their caregiving duties or the family's life becomes disrupted (Jubb & Shanley, 2002). In addition, financial stress can result because some patients are not self-supporting and lack financial resources (Potasznik, 1995). The financial stress combined with caregiving duties take a toll on the families' physical and mental health and can result in psychological distress, emotional difficulties, and stress related physical problems (Guarnaccia & Parra, 1996). To holistically assist the majority of the mentally ill population, it is important to

consider the family caregivers who hold an integral role in the treatment of those patients who have a mental illness and are living at home.

### **Research Purpose and Question**

The purpose of this narrative study was to better understand the lived experiences of family caregivers through different stages of their relative's mental illness. Examining narratives of their life histories provided a glimpse of the caregivers' world and revealed their daily realities in dealing with their mentally ill relatives.

This narrative study aimed to answer the following research question: What are the lived experiences of family caregivers living with a relative who has the diagnosis of schizophrenia or bipolar disorder through the different stages of the mental illness? In examining this question, a narrative inquiry using a chronological sequence of qualitative analysis (Creswell, 2007, p. 170) was used. The interview questions were divided into three main stages which centered on the mental illness life-course. Life-course stages are the stages in an individual's life experience that become the focus for the researcher in order to develop the chronology of the individual's life (Denzin, 1989). In this study, the three stages were the following: (1) life before the onset and diagnosis of the mental illness; (2) life during the onset and diagnosis of the mental illness; and (3) life after the onset and diagnosis of the mental illness. Under each of these stages, were 6 sub questions concerning: (a) the relationships of the family members with each other; (b) the family's relationship with society including stigma because of the mental illness; (c), the family's finances; (d) the family's emotional health; (e) help from mental health providers; and, (f) the family's coping skills and its methods of self-care (gaining strength, faith) (See Appendix B for a list of these questions).

Many quantitative and qualitative studies on family caregivers' burden and stress as a result of the caretaking duties have emerged since families have been entrusted with the role of caregivers. However, qualitative narratives about the lived experiences of the caregivers through the different stages of mental illness are still lacking. In addition, services to support the lives of caregivers and their mentally ill relatives are virtually non-existent even after much research shows that these services can help provide support to the family caregivers (Doornbos, 2002). Moreover, it is also important that the interventions and treatment for the mentally ill and their family caregivers be created with the collaboration of the families in question (Doornbos, 2002).

### **Significance of the Study**

This study aimed to understand the inner lives of those individuals caring for a mentally ill relative through three different stages of the mental illness of schizophrenia and bipolar disorder. Earlier perceptions related to severe and persistent mental illnesses have changed over the years, and the notion of recovery is becoming the goal of the public (Hutchinson et al., 2006). However, the process of moving individuals from an institution into a community or family setting has created many serious problems by challenging the families' caregiving abilities (Muhlbauer, 2008).

One of the problems reported by the caregivers is that society does not understand the scope of their caregiving or the extent of their interaction with the ill family member; they add that they are frequently devalued and dismissed (Muhlbauer, 2002). By understanding the lived experiences of the family caregivers, mental health providers may include the insights gained in their treatment goals. By including their knowledge about the families in their treatment goals, and by using the family caregivers' experiences instead of minimizing

their importance, mental health providers can create more effective treatment models for the mentally ill and use the family caregivers' support constructively. Moreover, it can provide the medical and mental health field with an added awareness of the issues surrounding the family caregivers because they are an important and inevitable link toward enhancing and maintaining any kind of treatment for the mentally ill.

In recent years, studies about the burdens faced by family caregivers have become the focus due to the rising number of family caregivers of the mentally ill. This study added to the literature by focusing on the differences in the caregivers' stress and burden throughout three different stages of the mental illness. It looked at the caregivers' lived experiences in relation to the development of the mental illness. By using the mental illness as the life-stage course, it aimed to look at an added component which was to look at each stage and its corresponding areas of psychological distress, stress, and burden. This kind of study may enhance understanding of the families' lived experiences and the obstacles that those families dealing with the mental illness of schizophrenia and bipolar disorder face on a daily basis.

As a consequence, this type of study may provide mental health professionals an added awareness for creating effective interventions for family caregivers dealing with the mental illness of schizophrenia and bipolar disorder by looking at the different stages of the mental illnesses. Psycho-educational training groups for family caregivers are linked with a reduced rate of relapse of mental illness (Heru, 2000). Miklowitz & Scott (2009) found that psycho-educational groups for families were linked with a reduced relapse rate for patients with bipolar disorder. In looking at the types of psycho-educational treatments for families, Heru (2000) found that for families dealing with chronic mental illness, rigorous training for learning coping skills in order to deal with long-term care and support were effective. Thus,

this type of study can help providers provide better training and education for the families involved by giving them more information about the types of coping mechanisms that are effective in preventing relapse in patients with mental illness and at the same time it may help them to distinguish the level of intervention needed according to the diagnosis of the mental illness and by its corresponding stage. In other words, by knowing about the progression of the mental illness, the provider may be able to distinguish the level of psychological distress the family caregivers are undergoing and tailor the interventions accordingly. It can also assist in developing training for long-term care and support for mentally ill patients.

Most studies in the area of caregivers of the mentally ill are focused on the burdens, stress, and psychological distress that family caregivers endure as a result of the caretaking. Studies on the satisfaction that family caregivers may experience as a result of the task of caretaking are limited. This study can open doors for research targeting the areas of satisfaction for caregivers which may become part of devising interventions that can empower caregivers and learn methods of gaining more satisfaction.

Finally, this study can be the catalyst for further studies in the area of mental illness and family caregivers. It may open doors for studying other mental illnesses in addition to the ones used in this study. This study also aimed to trigger the importance of finding ways to help such families. It pointed to the embedded awareness that if family caregivers get the much needed support and guidance that they require, then in the long run, society will benefit. In other words, by having more support for the growing number of families who are the caregivers of the mentally ill, society composed of such families will be better prepared to care for the mentally ill individuals. The knowledge that families are an important source

of treatment for the mentally ill can become even more prevalent. By seeing mental illness as a part of many families' lives, society may also become more tolerant and stigma as well as ignorance regarding mental illness can change. Hence, if mental illness is seen as an illness that can be controlled with proper medications and proper care, then stigma due to ignorance of the illness and ignorance of its prognosis will eventually be diminished. This can improve the quality of life for the mentally ill and their families.

Consequently, a narrative analysis of the life histories of such families can provide important insight for those who assist such individuals, as well as those who find themselves in a similar situation such as the family caregivers or other community members entrusted with the care of the mentally ill.

### **Conceptual or Theoretical Framework**

In trying to understand the impact of mental illness, Family Systems theory was used as a theoretical framework. According to this theory, the family is an interrelated system, in which all the members of the household affect each other. Thus, if a family member has a mental illness and the rest of the family members are living together, the illness affects everyone. One way to understand the impact of the illness on the family members is to look at Family Systems theory as described by Murray Bowen (1994). In Bowen's theory, the family is an emotional unit and therefore is a system. If something affects one individual in a family, it affects the whole family. Thus, if a person has a mental illness in the family, that affects everyone in the family. Family Systems theory looks at the emotional process among family members because the family is seen as a single unit (Gilbert, 2006). A more detailed description of family systems will be provided in chapter 2. By understanding this concept,

one can conclude that mental illness in the family affects the interpersonal process among the individuals and their relationships with each other.

### **Researcher's Background**

My own interest in this topic comes from my professional work as a therapist and my dedication to the field of human services. As an interpretive researcher, I seek to understand the meaning behind the individuals' experiences. I also consider myself to be a humanist researcher. The humanist view is one that states that a person is in charge of choosing his or her own behavior instead of reacting to environmental stimuli. It is a view that promotes issues that deal with the self-esteem of a person, and talks about the need for a human being toward fulfillment of the self and of their needs. Thus, it is a view that points to individuals' need for personal development. One major humanist theorist was Carl Rogers. Carl Rogers (1994) believed that each individual has his or her own way of building his or her self-concept. This concept according to Rogers is fostered through two terms that he described as unconditional positive regard and conditional positive regard. When someone accepts a person and offers unconditional love, then he or she is giving unconditional positive regard. When someone's love is conditioned on some condition being met, this according to Rogers is conditional positive regard. As a client centered therapist, Rogers felt that the feeling of being accepted without any conditions was the vehicle for healing for the client. As a client-centered therapist trained with Rogerian techniques and Roger's philosophy, I do believe that human beings have the ability to make choices. Individuals aim toward self-fulfillment. When looking at the life histories of the family caregivers involved in this study, my focus was to look at the ways they strived toward self-fulfillment despite the burdens they may have faced while dealing with mental illness. I looked at the way that the individuals

responded to the mental illness and of giving care to their mentally ill relative. I looked at how the experiences of caregiving may have been connected to their own ways of looking for areas of self-fulfillment. In addition, I also looked at the caregivers' experiences by framing the experiences into three different stages of the mental illness which were associated with the time before, during, and after the onset and diagnosis of the mental illness. This was done to gain an understanding of the types of stress and burden associated at each stage of the mental illnesses of schizophrenia and bipolar disorder.

In studying the family and the impact of mental illness on the family, I was also interested in finding out if the family caregivers had any support from other people who were not in a situation similar to theirs. What does a person who has to oversee someone else's daily life, perhaps for an indefinite amount of time, feel or think? How does that person see his or her own life and understand reality vis-à-vis the illness? I believe that the stories of such individuals need to be told and heard. These stories take us closer to our individual search or dilemma. They help us see the truth of one or a few individuals and understand the depth of the human condition.

Therefore, this qualitative study of family caregivers aimed to understand the meaning of the subjective experiences for the individuals involved, as well as for those interested in making a difference in the lives of such individuals. My lens as a therapist is something that is part of my own way of looking at the world. I also believe that a person-centered approach was effective for this study because the interview process brought up feelings of emotional pain or trauma in the subjects being interviewed. Having been trained in dealing with pain and trauma helped me understand my subjects better, and also aided me to detect areas that needed to be healed. Thus, this knowledge also made it possible for me to

understand the necessity of referring the individuals for mental health treatments if the need arose during the interview process. I believe that providing the interviewees with a supportive, and non-judgmental attitude of unconditional positive regard, as well as an empathic style (Rogers, 1994), enabled the participants to feel as supported and understood in telling their life histories as clients do in person-centered therapy settings.

I believe that all matters that take us deeper into our beings, buried deep in our hearts, can be compared to brave journeys where the explorers can expect the unexpected. Interviews that look at the life histories of individuals dealing with mental illness are such journeys. The unexpected is bound to happen and, for this, a person trained to handle trauma and healing is best equipped for the understanding and sensitivity required when dealing with such matters. I believe that an open-ended interview style can help build the relationship that is necessary between the participants and me, as the researcher, to foster exploration of what has perhaps become dormant in the participants' beings.

### **Definition of Terms**

Some of the key terms that will be used in this study will be defined here.

#### **Mental Illness**

Mental illness as defined by NAMI (National Alliance of the Mentally Ill, n.d., 05/03/2011) is a medical condition that disrupts a person's thinking, feeling, mood, ability to relate to others, and daily functioning, which typically results in a decreased ability to cope with the ordinary demands of life.

#### **Psychosis**

Psychosis refers to a psychological state in an individual who has delusions or severe hallucinations. A broader definition includes positive symptoms of schizophrenia,

which are disorganized speech and grossly disorganized or catatonic behavior, as described by the American Psychiatric Association (2000).

### **Bipolar Disorder**

Bipolar disorder, also known as manic-depressive illness, is a brain disorder that causes unusual shifts in mood, energy, activity levels, and the ability to carry out day-to-day tasks. Symptoms of bipolar disorder are severe. They are different from the normal ups and downs that everyone goes through from time to time. Bipolar disorder symptoms can result in damaged relationships, poor job or school performance, and even suicide. Bipolar disorder can be treated, and people with this illness can lead full and productive lives.

(NIMH, n.d., on 05/03/2011).

### **Schizophrenia**

“Schizophrenia is a chronic, severe, and disabling brain disorder that has affected people throughout history. People with this disorder may hear voices other people don't hear. They may believe other people are reading their minds, controlling their thoughts, or plotting to harm them. This can terrify people with the illness and make them withdrawn or extremely agitated. People with schizophrenia may say things that people do not understand. They may sit for hours without moving or talking. Sometimes people with schizophrenia seem perfectly fine until they talk about what they are really thinking. Families and society are affected by schizophrenia too. Many people with schizophrenia have difficulty holding a job or caring for themselves. For this reason many people with schizophrenia may rely on others for help”

(NIMH, n.d., on 04/17/2013)

**Tardive Dyskinesia**

This term describes a condition that may develop in patients with the usage of metoclopramide, which is a drug sold under brand names such as Reglan in the United States. When a patient has been taking certain prescription drugs over a long period of time, involuntary repetitive tic-like movements may result. They could develop mainly in the facial muscles or sometimes in the limbs, fingers, and toes. At times the hips and torso may also be affected (n.d. retrieved on line 10/26/2013)

**Psychological Distress**

This term defines caregivers experience of feeling low energy, emotional upset, and of having sleep problems. The psychiatric symptomatology was found to be higher in caregivers of the mentally ill than in a normative sample (Winefield and Harvey, 1993).

**Burden**

This term refers to the presence of unfavorable problems, difficulties, or unpleasant events that affects the life of psychiatric patients (Ganguly, Chadda, and Singh, 2010).

**Objective Burden**

This term refers to the physical burden of care that the caregivers experience as a result of their mentally ill relative's behavioral changes. This type of burdens includes disruption in household routines, missed days from work, and physical tasks. It also includes the social effect (Ganguly et al., 2010).

**Subjective Burden**

This term refers to the emotional burden that caregivers experience such as frustration, anxiety, depression, and emotional reaction to the strain of the caregiving duties. (Ganguly, et al., 2010).

## **Summary**

The aim of this study was to look at the experiences of the caregivers' lives and understand their lived experiences in dealing with their relatives afflicted with mental illnesses of schizophrenia and bipolar disorder. This section began with the introduction of this study and explained how the caregivers of the mentally ill were entrusted with the care of their mentally ill relatives as a result of deinstitutionalization. The problem statement for this study arose from the fact that more than four millions American families are entrusted with the caregiving of their mentally ill relatives, yet the interventions and preventions of the western medical model mainly focus on the individuals with the mental illness and not on the family as a whole. A definition of the terms used in this study was provided in order to facilitate the understanding of schizophrenia and bipolar disorder as well as the terms that accompany these two illnesses. A chronological sequence of qualitative analysis was used to examine life course.

This study was conducted using narrative inquiry as the methodological framework. Family Systems theory was used as the theoretical framework to analyze this study. In addition this section concluded with a description of the significance of this study.

## **Chapter 2: Literature Review**

This chapter will examine relevant studies which were influential in building the foundation of this literature review regarding family caregivers of the mentally ill. First, it will present the historical implication of deinstitutionalization that came about as a result of anti-psychotic medications. Next, important studies on the burden, stress, and psychological distress experienced by family caregivers will be presented. This chapter will also describe about the coping mechanisms that can diminish stress for caregivers as well as information about the types of interventions that have been helpful for family caregivers of the mentally ill. In addition, this chapter will provide a definition and an overview of family systems theory. In order to facilitate the understanding of the stages of mental illness, a description of bipolar disorder and schizophrenia will be provided.

Finally, this chapter will conclude with relevant research about the effects of bipolar disorder and schizophrenia on the brain. Information about preventing recurrence of mania or psychotic episodes and further damage to the brain which affects the person's cognitive and emotional functioning will also be provided.

### **Changing Perceptions about the Mentally Ill**

In the 1950's, families of the mentally ill were blamed for the mental illness of their relative (Guarnaccia, P.J., & Parra, 1996). In particular, initial studies concluded that families were to blame for their mentally ill relative's pathology, and the family was viewed as being dysfunctional (Muhlbauer, 2008). Prior research by Gubman et al. (1987) found that the reasons for mental illness were linked to the family's way of communicating and interacting. In addition, Bateson's (1960) "double-bind theory" was about blaming the mother for sending contradictory messages to her child, causing a "mental split," and thus

becoming schizophrenic. The mother in that theory was labeled as the “Schizophrenogenic Mother” and schizophrenia was attributed to the mother’s personality, behavior, and to her emotions (Bateson, 1956; Lidz, Fleck, & Cornelison, 1965). Thus, if the mother was to blame for her child’s illness, the child needed to stay away from her, which justified the practice of hospitalizing patients for extended periods of time (Jubb & Shanley, 2002).

In the 1970’s, the perception of blaming families for mental illness started to change (Jubb & Shanley, 2002). Goldman (1982) found that the family, in many cases, had a positive influence on the person’s illness. More current research (Kuipers, 2006) showed that the reason for psychotic relapse in schizophrenic patients was due to the family’s expressed emotions (hostility, criticism, and over-involvement of the parents). Consequently, the parents were more implicated in the reoccurrence of the symptoms and not in the causation of the illness (Seeman, 2009).

Moreover, the introduction of medications that reduced psychotic symptoms generated a movement to semi-independent or independent living for the mentally ill (Muhlbauer, 2008) which started the concept of community-focused care (Jubb & Shanley, 2002). Most of the time, it was family members who became the main caregivers for their mentally ill relatives. It was families who were entrusted with the task of taking on the responsibility of monitoring patients who were still symptomatic following hospitalizations for illness-related crises (Rose, Mallinson, & Gerson, 2006). Today the parents of schizophrenic patients are seen more as people who are suffering along with their children because of the burdens associated with caregiving (Goldman, 1982).

In summary, in the last 60 years the attitude toward the mother of the schizophrenic child has greatly changed and the mother and the family caregivers are seen as people who are burdened by the task of caregiving (Goldman, 1982).

### **Burden, Stress, Psychological Distress, and Stigma**

Family caregivers of the mentally ill experience different types of stress and other related factors such as psychological distress (Winefield & Harvey, 1993), social isolation, and stigma (Rupert & Mayberry, 2007).

**Burden and stress.** One of the outcomes of caring for a mentally ill person is the burden and stress that the families feel as a result of caretaking duties (Rose, Mallinson, & Gerson, 2006; Fujino & Okamura, 2009). Burden has been defined in many ways. According to Heru (2000) burden “includes measures of subjective and objective distress, as well as measures of the way in which a caregiver’s life-style has been altered by financial difficulties, curtailed activities, loss of vacations, etc.” (p. 96). Heru (2000) as well as Jubb & Shanley (2002) distinguished two types of burdens affecting families of the mentally ill. The first type is an objective burden, which refers to the observable costs resulting from the mental illness, such as disruptions to the daily lives of the family caregivers, financial expenses, or changes in the family’s daily schedule. The second type of burden is called subjective burden, which is the individual’s judgment about his or her own life and the burden that he or she feels is being carried. According to Jubb & Shanley (2002), subjective burden is associated with the physical and mental well-being of the family members, and includes depression, anxiety, or guilt. They hold that subjective burden in families can include a sense of feeling isolated and lonely. Furthermore, families may also feel the burden of being stigmatized and, thus, become even more isolated (McInstosh & Zirpoli,

1982). In general, families experience greater distress from the subjective burden (Ostman & Hansson, 2000).

**Psychological distress.** Winefield & Harvey (1993) found that among the caregivers of patients with schizophrenia, the psychological distress (low energy, emotional upset and sleep problems) and psychiatric symptomatology were found to be higher than in a normative sample. Rupert & Mayberry (2007) also concluded that the family members of the mentally ill are faced with social isolation, financial difficulties, and psychological stress. They face the isolation of the stigma that their loved one faces because of the illness and the difficulties that arise because of the implications of the illness. Rupert & Mayberry (2007) affirm that for the most part, caregivers of the mentally ill have many symptoms of depression and psychological problems. There is also a correlation between mechanisms of coping, caregivers' sense of burden, and the behaviors of the ill person (Lively, Friedrich, & Rubenstein, 2004).

One of the main reasons for psychological distress in caregivers is related to the mentally ill person's behaviors (Scheirs & Bok, 2007). These disruptive behaviors from the mentally ill relative in turn create more emotional and psychological distress for the caregivers. Some of the examples of disruptive behaviors are excessive talking, throwing and destroying furniture, talking to themselves, and waking up in the middle of the night. For example, in one family, the mentally ill family member "left in the middle of the night to wander the streets, turned on appliances such as stoves and washing machines, or woke up sleeping relatives demanding money or cigarettes." (Rose et al., 2006, p. 49). Thus, the relationship of the family members with the mentally ill relative is laden with behavior problems that can cause psychological and emotional distress in the caregivers.

**Stigma.** Another factor affecting the lives of the family members is the stigma that the mentally ill face in our society. People with mental illness experience all of the main features of the stigmatizing process including feeling labeled, being isolated, connected to detrimental stereotypes, and largely discriminated against (Link & Phelan 1999). According to Corrigan, Watson, & Miller (2006), stigma not only harms the mentally ill, but also extends to their family members who are perceived as being connected to the mentally ill person. Goffman, (1963) calls the stigma experienced by family member's *courtesy stigma*. *Courtesy Stigma* is the prejudice and discrimination that is extended to people not because they themselves have some mental disorder but rather because of their link to the mentally ill person. This implies that the family members also experience the stigma associated with the mental illness because of their connection to the mentally ill relative. For instance, in a study by Yang and Pearson (2002) where they studied schizophrenia in Chinese families, the researchers stated that the stigma of mental illness created a loss of face and negatively affected the family's prestige in society. The Chinese families used strategies to minimize the stigma of mental illness by not participating in social activities in order to avoid embarrassment; the stigma itself deterred the family from looking at social networks that could lessen isolation which also discouraged them from participating in any support groups (Yang & Pearson, 2002).

In another study by Corrigan et al. (2006) researchers found that psychiatric disorders were seen as more blameworthy than physical health conditions, such as cancer or heart disease. Sometimes the family of the mentally ill is blamed for the onset of their relative's disorder and relapse; they are also seen as unskilled family members (Corrigan & Miller, 2004). This implies that society blames family members for the mentally ill person's

disorder and holds them responsible for any relapse. Often the stigma experienced by family members leads to feelings of shame, contamination, or guilt (Corrigan et al., 2006), which reduces a person's quality of life. Because of the potential for stigma, family members may not disclose their relative's illness in public. The stigma of mental illness, based upon the inclination of society to see mentally ill persons as weak or dangerous, may also contribute to the burden experienced by the family caregivers. Rose et al. (2006) found that the families of the mentally ill were bothered by media stories that showed mentally ill persons as losing control and killing someone.

Moreover, research indicates that stigma varies according to family roles. Corrigan & Miller (2004) discovered that siblings and spouses are often blamed for family members' mismanagement of the illness. In a study of 164 siblings, researchers found that the participants were concerned about their relatives' adherence to treatment regimens because they felt that if the ill relative relapsed it would be their fault (Greenberg, Kim, & Greeley, 1997). In a similar study, researchers found that siblings experienced less shame when they did not live with the mentally ill relative, compared to the ones who did (Phelan et al., 1998). Corrigan et al. (2006) stated that in cases where a parent had a mental illness, the child was often viewed as "contaminated" (p. 240).

### **Interventions**

The types of well-researched interventions considered to be helpful for families of chronically mentally ill patients are psycho-education treatments that provide training and coping skills for families, as well as long term support (Heru, 2000). Fujino and Okamura (2009) found that providing support to enhance the quality of life for individuals suffering from mental illness might indirectly help to decrease the sense of burden felt by the family

members who are caregivers. According to Sherman and Carothers (2005), interventions for chronic mental illness are shown to be highly effective for the improvement of social functioning, providing information to family caregivers about the mental illness, and eventually reducing the cost of the caretaking burden. However, few families receive these services. In addition, according to a study conducted by Biegel, Robinson, and Kennedy (2000), educational and psychoeducational interventions helped to decrease the burden experienced by family caregivers by improving family functioning and by helping the caregivers acquire better coping strategies. This in turn improved the mental health of the family caregivers. They also found that a longer psychoeducational intervention group for the mentally ill was associated with a reduction of symptoms and with an improvement in the family's relationship with the relative with the mental illness.

Another area that helps to reduce stress for families is the level of mastery over the illness. The level of mastery in one study referred to the caregivers' sense of control over managing the illness (Rose et al., 2006). The researchers felt that the higher the level of mastery over the illness, the lower the stress and burden the family caregivers felt. If a higher level of mastery helps to reduce the stress felt by the family members, interventions providing them with some mechanism and information to raise the mastery level will eventually help decrease the level of burden and stress. This study also affirmed that interventions specifically targeting the grief and loss that the family members feel as they learn to accept the illness are an important area of focus for professionals in the field of mental health.

Rose et al. (2006) affirm that in addition to providing assistance with the grief and loss that families experience, healthcare providers should also give families accurate and

current information about the prognosis of the illness. They also added that interventions should be tailored specifically for each family and include needs of siblings. This shows that many families need more information about the illness and its prognosis. By learning more about the illness, family members can be more helpful. Tailoring the interventions specifically for each family will provide them with a better outcome.

Even if the family is no longer being blamed for the mentally ill person's illness, the family is still not being fully integrated into the treatment models for the mentally ill. Interventions targeting the real needs of the caregivers are scarce. In order to help the mentally ill and their families, it is important to understand the daily reality of the caregiver's lived experiences in order to shed light on those areas that can improve the quality of life for the mentally ill and their family caregivers.

### **Family Caregivers of the Mentally Ill**

A study of caregivers of people with severe mental illness by Chiu, Wei, & Lee (2006) was conducted in Hong Kong and in Taiwan. In depth-interviews of 11 caregivers of relatives with severe mental illness were conducted. The interviews were audiotaped and transcribed into verbatim texts. The texts were narratives by the caregivers and were analyzed using open coding. Various themes relating to the caregivers' concerns emerged. The five major themes were: (1) mystical knowledge beyond understanding, (2) having no confidence in recovery, (3) persistent self-blame and explanation, (4) inertia of caregivers and non-responsive system, and (5) unsatisfying encounter with medical staff. Mystical knowledge beyond understanding referred to the caregivers who stated that the mental illness was beyond their understanding and that it was something mystical that only a doctor could understand. They also stated "they could do nothing" (p. 416). They did not comprehend

medications and stated that only experts could understand the illness. The theme confidence in recovery referred to the caregivers' feeling that there was no cure for the illness and that there was no chance of recovery. According to the researchers, one of the reasons why the caregivers did not have confidence in recovery was because the Chinese concept of recovery is taken to mean total recovery. Hence, for the caregivers, slow progress of symptom control and psychosocial functioning of the mentally ill relative meant that there was no chance of recovery and they were hopeless about recovery. The theme called persistent self-blame referred to the caregivers' feeling that they had done something wrong to provoke the mental illness. Sometimes, they even blamed themselves for the relapse. Inertia of the caregivers, referred to the caregivers' action of not asking for services beyond the psychiatric follow up. They either did not know or felt that no one informed them about the services available such as counseling for the mentally ill relative or the family members. Finally, the last theme unsatisfying encounters with the medical staff, referred to the caregivers' feeling that they were not getting the information they needed when it came to helping the family caregivers. One woman talked about being turned away when she asked for counseling for the families. The caregivers also stated that "they (the medical staff) talk as they know everything, but they did not hear the voices of the family. "They are hugely distant from the needs of the family" (p. 418). In this study, the researchers concluded that the caregivers did not communicate their concerns to the doctors because in Chinese culture, patients regard medical doctors with high regard and may not be able to voice their concerns because of the cultural education of not wanting to offend anyone. Thus, the caregivers may have seen the expression of their dissatisfaction as something that would have been regarded as offensive. For this reason, the health care providers were not aware of the needs of their patients and

their families. When the recovering patients were not getting the help that they needed, they started to lose trust in the system. On the other hand, the medical staff was also frustrated with the allocation of unfair resources which made it difficult for them to do more outreach.

Chiu et al. (2006) also concluded that one of the ways that society can improve the lives of the mentally ill and their families is by improving the health and social care system. Other researchers (Jubb & Shanley, 2002) agree that policies and provisions should be made within the health care system to promote participation by the family members and caregivers.

Ganguly et al. (2010) conducted a study on the caregivers' burden and coping skills for persons who were diagnosed with schizophrenia and bipolar affective disorder. This study was conducted in an out-patient setting at the Institute of Human Behavior and Allied Sciences in New Delhi, India. This was a longitudinal study where the researchers conducted focus group discussions with 100 caregivers caring for a relative with either schizophrenia or bipolar affective disorder. The purpose of this group was to obtain detailed information on the caregivers' experiences with their mentally ill relatives. The data collection took about a year. The focus group data was then analyzed as narrative text by a medical anthropologist. Analysis of data showed that the caregivers in this study experienced the following burdens: (1) social isolation, (2) restriction in their social life and leisure activities, (3) financial stress, (4) health- related problems, (5) social stigma, and (6) impact on their family functioning. In describing social isolation and stigma from society, one of the family caregivers talked about how people in his neighborhood and even his close relatives stopped coming to his home. Another caregiver who was the father of a young unmarried woman with schizophrenia said that he had to hide the disease from people because he was afraid that people would not marry his daughter and his family could not talk about their feelings to anyone. Other

statements from caregivers regarding social stigma included the mentally ill are looked upon as being inferior and people avoiding the mentally ill and scolding them. “The person with the mental illness is frequently blamed for his or her problems and is misunderstood by the general public” (Ganguly et al., 2010, p. 133). In describing the effects on family functioning, the wife of a person with bipolar affective disorder said that her children were not able to concentrate on their studies because of their father’s problems. When describing the financial burdens, a family caregiver who was the wife of man with mental illness said: “Once he ran away with all the jewelry, and after that our financial position got worse” (p. 133). Another wife of a mentally ill man said that she was the main wage-earner in the family and that her husband was not able to work on a regular basis which placed great financial burden on the family. In India, the mentally ill do not get disability money from the government. This creates great financial strain on the families.

In addition to burdens experienced by caregivers, this study found the following coping strategies that caregivers used in dealing with their mentally ill relative. They were: (1) a positive and compassionate approach with the mental illness, (2) religious support, (3) self-help approach (where the caregivers found ways to help themselves, (4) acceptance of the illness, (5) hopefulness about the future, (6) supportive handling, and, (7) taking advice from experts.

A positive and compassionate approach with the mental illness was when the caregivers learned to be more open to the illness and more understanding of their relative’s illness. Religious support referred to the caregivers’ having faith in God which was voiced as being the most important coping strategy. The caregivers in this study talked about “doing one’s duty to take care of their relative with illness and provide him or her with the best

treatment and leave everything to God” (p. 136). Self-help approach referred to the caregivers looking for ways to help themselves or help others learn about the illness. Another good strategy was acceptance of the illness. One caregiver explained that his family had to argue with everyone else and explain that the mentally ill relative “was not doing it intentionally” (p. 136). Some other helpful coping mechanisms were supportive handling which referred to family caregivers tackling the mentally ill person’s behavior with supportive comment to ease the disruption or hopefulness which referred to the family caregivers always having good hopes for the future.

In a study by Rose et al. (2006) the researchers examined the impact of serious mental illness on family life and family functioning. They used a mixed method design. Telephone interviews of 30 family members of mentally ill relatives were conducted. The researchers studied the following areas in order to understand specific areas of caregivers’ concerns. They were: (1) the different types of caregivers’ burden, (2) the different aspects of caregivers’ burden that created the greatest concern, (3) the ways that a family dealt with the different levels of severity of the illness, and (4) the relationship between the sense of mastery over the burden, perceived illness severity, and the family caregivers’ concerns. For the purpose of their study, the researchers collected data from two types of methods: (1) structured questionnaires, and (2) open-ended questions. The families were selected from two local community based support groups (the National Alliance of the Mentally Ill and The Depression and Related Affective Disorders Association). The families were those families who had a relative with schizophrenia, bipolar disorder, or major depression. Rose et al. (2006) discovered that the greatest burden that families described was “worry about the future” and “dealing with sadness and grief” (p. 41). The worry about the future referred to

the families' thoughts about how the mentally ill relative would survive without the caregivers' emotional and financial support. The sadness and grief suggested that families were "resigned to the patients' condition, but wished that the patient's functioning could be improved" (p. 49). The grief was also the product of the family caregiver's realization of the life that the mentally ill member had lost. The caregivers described their feelings of loss and grief as a sense of having "lost the person to the illness with the lingering hope that the (healthy) person would return and the family would, again, experience good times" (p. 47). Additional sources of burden for the family caregivers were: "not doing enough for the mentally ill relative" where the caregivers felt that they could always do more or try a different approach, "upset household routine" such as not being able to take vacations and living in a constant state of crisis, "stigma" where the family members were embarrassed by the mental illness because of the stigma that they experienced, "handling disruptive behaviors" which referred to the effect of the patient's disruptive behavior on the family unit, and "how to talk to the patient" which referred to the families' concern about how their interactions with the ill member could be more effective (p. 47-48). Rose et al. (2006) concluded that the mental illness created key changes in the functioning of the family. The family was always in a state of persistent crisis; many internal conflicts were present. They also stated that families in general were seeking information in order to improve daily living conditions with their mentally ill relative. Thus, family members suffered different types of burdens and in order to help the mentally ill relative it was important to investigate their daily living experiences with the mental illness.

In a study of 76 family caregivers by Doornbos (2002), written narrative responses about the supportive and non-supportive aspects of the mental health system as well as the

desired services were analyzed using content analysis. The family caregivers were recruited from the National Alliance for the Mentally Ill (NAMI). The findings suggested that families felt a need for earlier prevention to prevent a crisis. The family caregivers felt unprepared for the tasks of the caregiving role and wanted more information about how to be more prepared. They wanted to be able to have better training, have more peer support, and be able to talk to health-care professionals. They also asked for professional recognition of their role in the treatment of their mentally ill relatives. Another area of expressed need for the family caregivers in this study was getting help with housing and vocational training for their relatives. In addition, the family caregivers felt that the larger system should change as well to accommodate the needs of the mentally ill and their caregivers. In describing the changes of the larger system, the family caregivers expressed a desire for a collaborative effort between mental health professionals and family caregivers in fighting parity for insurance coverage and allocation for additional tax dollars for mental health services and research. Similarly, the family caregivers called for combined efforts directed toward erasing the stigma and alienation associated with mental illness (Doornbos, 2002). “The task now is to find a way to translate empirical findings into the interventions that will provide support for the family caregivers” (Doornbos, 2002, p. 43).

The following was a study conducted by Huan, Sun, Yen, and Fu (2007) in Taiwan. The purpose of the study was to understand the coping experiences of family caregivers who lived with a relative who was diagnosed with schizophrenia. A qualitative descriptive phenomenological research method was used. Purposive sampling and face-to-face interviews were conducted to collect data. The sample was purposive and 10 family caregivers of mentally ill relatives were interviewed. The two coping mechanisms that were

prevalent in this study were psychological coping mechanisms and social coping mechanisms. Examples of psychological coping mechanisms were: (1) positive thinking and acquiring knowledge, (2) keeping busy and/or pursuing personal interests, and (3) crying and not accepting the illness which increased the stress level in the family caregivers. One parent said: “I can’t accept my son’s illness and he has been ill for 18 years. I am always crying. How can I accept this situation?” (p. 822). Examples of social coping mechanisms in this study were: (1) becoming more spiritual or religious, (2) gaining more support from family and friends, and (3) getting professional support from the providers. This study concluded that in order to assist family caregivers of the mentally ill it is important to understand their coping mechanisms.

Another study by Rammohan, Rao, and Subbakrishna (2002) looked at religious coping mechanisms and their relationship to the psychological well-being of family caregivers of people with schizophrenia. They assessed sixty family caregivers on their strength with religious beliefs, perceived burden, religious and other coping strategies, and psychological well-being. Two hundred and five patients and their caregivers participated in this study. In addition to questionnaires, semi-structured interviews about the caregivers’ religious beliefs and practices were conducted. The results indicated that religious beliefs and religious practices enhanced the well-being of the caregivers. They concluded, in addition to psychoeducation and problem solving, religious coping mechanisms should be incorporated into family intervention programs.

In summary, studies on family caregivers’ burden, stress, and coping mechanisms with mental illness include burden and stress associated with the behaviors of the mentally ill relatives, financial stress, lack of social support from friends and community, effect on

emotional and physical health, lack of understanding about the mental illness, worry about the future, lack of support from mental health providers, dissatisfaction with treatment, and problems associated with the system at large such as the ones that influence insurance policies and help from federal and state government. The coping mechanisms that family caregivers used included understanding and accepting the illness, being hopeful, getting more knowledge about the illness, connecting with family and friends for social support, finding ways to tackle the mentally ill person's behavior, finding religious support, and finding support from the professionals in the mental health field.

### **Family Systems Theory Overview**

For this proposed inquiry the family systems theoretical approach was used which deemphasizes the notion that conflicts and anxieties are due primarily to the makeup of individual personalities, and suggests instead, that individual problems have more to do with relational networks, the makeup of others' personalities, where one stands within the relational systems, and how one functions within that position. Family systems theory is founded on the belief that the family is a system (Friedman, 1985). To fully understand this theory, it is helpful to first examine systems thinking

Systems thinking departs from the traditional notions of cause and effect to consider how the individual parts of a system are interdependent upon one another and connected to every other part. Additionally, with systems thinking, one looks at how each part affects the whole, and examines the position of each part within the system. (Freidman, 1985). Systems thinking require that individuals do not label or diagnose a problem without looking at the whole picture (Bregman & White, 2011).

When systems thinking is applied to the family process, one can then understand “symptoms” in a different way, in terms of interdependent variables. For example, when considering trauma through the lens of systems theory, one looks at the emotional system of the family and the way that system promotes or expands the effect of the trauma. One would look not only at the trauma but also at other factors within the family system that affect the trauma. Family systems theory focuses on the systemic forces of emotional process rather than on the content of some symptom. To create change and eliminate symptoms, family systems theory looks at modifying the structure, rather than trying to directly change the dysfunctional part. Thus, one mainly focuses on the way a part is likely to function by observing its position within the system. This theory does not only focus on the dysfunctional part. It looks at the whole system (Friedman, 1985).

Bowen (1994) was the founder of family systems theory. Bowen created this theory after studying the human family as a living, natural system. He looked for consistency between the theory’s concept and knowledge by comparing it to the rest of the life sciences. Bowen theorized that there was an emotional link between the human and other life forms. While describing human emotions, Kerr and Bowen (1998) believed that the emotional system includes genes, mitochondria, cell membranes, intercellular connections, extracellular fluids, organs, tissues, and physiological systems. The emotional system also includes all the emotional reactions which support these mechanisms. Bowen believed that a human being’s behavior was largely governed by processes that predate the development of his or her complex cerebral cortex. He distinguished between emotions and feelings and believed that feelings can be felt while emotions operate outside of awareness. This separation between emotions and feelings, allowed Bowen to apply the term emotional to all living things. Kerr

and Bowen (1988) concluded that the emotional functioning of family members was dependent on each other and the family could be classified as an emotional unit. This implied that the family had a deep, multi-generational connection between family members and that it influenced the behaviors of its members beyond their conscious awareness. The family was considered as one organism. Family systems theory was founded on the premises that pathology in an individual member of the family is seen as a symptom of imbalance in the family's emotional system. Individuals develop symptoms because the emotional system gets out of balance (Vermont center for family studies, n.d. retrieved on line on 11/22/2013)

In this study, five different concepts from family systems therapy were used: (1) Homeostasis and circular causality, (2) Emotional triangles, (3) The identified patient, (4) Differentiation of self, and 5) The extended family (Friedman, 1985; Bowen, 1994). These five concepts are briefly defined in the following section.

**Homeostasis and circular causality.** Family systems theory is concerned with focusing on the family as a unit, rather than on its individual members. One method of maintaining the system relies on the concept of homeostasis. Homeostasis in family systems theory pertains to the propensity of any set of relationships to continuously look for a way to keep the system in place and to balance itself in order to achieve overall balance. Family systems theory assumes that any system exists because it has achieved balance that ensures its continuity and preserves its identity. In looking at a symptom, a family systems theorist is interested in finding out what happened before the symptom surfaced, and what kind of balance the symptom is trying to achieve. What is most significant is that family systems theory examines the position of the person in the system instead of examining the personality of the individual with the symptom. (Bowen, 1994; Friedman, 1985).

In order to gain a deeper understanding of how family members try to keep balance or maintain homeostasis, Friedman (1985) recommends that a family theorist look at what kind of system was in place in the family unit before the symptom appeared. In general, the symptom appears due to the system's natural tendency to try to balance itself and to try to re-establish the prior state.

Another mechanism that is used to keep homeostasis in the family unit is the concept of circular causality. Circular causality points to the fact that in family systems, each person's behavior in the family is caused by another family member's behavior. Thus, all the behaviors impact each other in a circular manner (Friedman, 1985). Nichols (1984) describes circular causality in family systems as the concept that events are related through a series of interacting loops or repeating cycles.

**Emotional triangles.** The basic principle of emotional triangles is that when any two parts of a system become uneasy with one another, they will triangle or focus upon a third person, or issue, with the purpose of stabilizing their relationship with one another (Friedman, 1985). Looking at the function that an emotional triangle is providing can expand understanding of the illness in the family unit. This can help to clarify some of the conflicts in the family.

**The identified patient.** According to family systems theory (Bowen, 1994), the family member with the symptom is not the "sick one" but, rather, the one in whom the family's stress or pathology has surfaced. Keeping this aspect in mind, the whole family is seen as an emotional unit. The identified patient is the one carrying the symptomatology but it is believed that any change is more likely by changing the whole unit, or family. If one were to treat only one person's symptoms without understanding the family process, those

symptoms would recycle in the same person in a different form, or transfer to another family member.

**Differentiation of self.** Bowen (1994) suggested that one of the main factors for change in any family has to do with the level of differentiation found in previous generations. Differentiation is the capacity of a family member to define him or herself apart from the cohesive family unit (Bowen, 1994; Bregman & White, 2011). Families fall within a scale of differentiation that is either a little advanced or a little delayed in maturity, compared to parents and grandparents. Usually, the children from a family marry people who are in a range similar to their own and similar to their families of origin. If individuals are less mature (less differentiated) then their children will most likely be less mature (less differentiated), and they will be less likely to welcome any change in their family systems. In other words, those children will be less equipped to deal with crisis. Hence, the less mature the individuals, the more resistant to change they will be. On the other hand, if the family generational pattern is one where the individuals are more mature (more differentiated) then the individuals in that family will be more equipped to change and be less resistant to make that change. The level of maturity and self-differentiation in the family unit may make a difference in the way the family members deal with or handle the complications associated with the mental illness.

Bowen (1994) created a differentiation scale that provides mental health providers with a scale to measure the level of differentiation of an individual (n.d. Ideas to Action, retrieved on 07/3/2013). On this scale, a person is classified with a certain level of emotional maturity. Its opposite is emotional regression. This scale differentiates the level of anxiety that each individual takes in which determines that individual's level of emotional maturity.

The functioning of the individual is then determined by the interaction of two important ingredients, feeling and thinking. The individuals at the lower end of the scale (which is feeling) will experience higher anxiety and the ones at the higher end of the scale (which is thinking) will be able to separate their feelings from their thoughts easily and will be more emotionally mature. Thus, an individual on the lower end will have more difficulties with his or her feelings and will react more to feelings and will be “more fused” with other persons. Fusion according to Bowen (1994) is when one part of a person mixes with another person. This scale accentuates the idea that if a person is determined to look at his or her level of differentiation and strives to become more emotionally mature, he or she can do so by understanding the interplay of his or her own thoughts and feelings. This will allow the person to better handle emotional fusion and disagreements in personal relationships. An emotionally mature person is more emotionally aware of the interplay of thoughts and feelings and is more internally balanced. This person is better equipped to handle external changes in personal relationships. This implies that the persons who are more fused or more feeling oriented can become more fused and undifferentiated with the other person’s problems. Bowen (1994) believed that differentiation helps one to be able to manage important relationships and by managing important relationships a person becomes more autonomous.

### ***Murray Bowen’s Scale of Differentiation***

#### **0 to 25-**

People in this range of intense emotions or fusion live with the greatest amount of life problems. In this range, people experience intense emotions or fusion. They can lose a separate self in relationships with others at this stage. It is hard for them to

accomplish their goals. People act in a certain way in a family unit and bear symptoms in order to protect others from anxiety.

**25 to 50-**

People at this stage are more focused on what feels right and become unbalanced when something is not harmonious. They are more functional than those at the 0-25 scale except when they are presented with something that is stressful. Nevertheless, people at this stage find it difficult to remain completely focused on their life goals. If there are no conflicts with other people then the individuals at this stage can accomplish their personal goals and excel.

**50 to 60-**

These people can adapt to changes in relationships. They know how to enjoy both goals and relationships with others. They are more balanced and remain neutral about others because they are balanced with their own thinking and feeling processes (Ideas To Action, n.d. retrieved on 07/13/2013).

**Extended family.** Extended family refers to the nuclear family or family of origin, but also includes other relatives such as aunts, uncles, grandparents, cousins, etc. (Friedman, 1985). Unlike the individual theoretical models that focus on the immediate family, family systems theory considers the entire extended family. It also considers the significance of the network of family connections. Gaining a better understanding of the emotional processes of a family of origin, and changing the responses to them can help considerably resolve issues within the immediate family. Hence, when family members bring up families of origin and their histories, a family theorist looks for patterns established by families of origin and their

effects on current problems. By knowing something about the extended families, one can gain understanding of the positions that each individual occupies within the family.

Family systems theory can help researchers understand how mental illness is integrated into the family and how it is experienced on a daily basis by the caregivers involved. By understanding the concept of systems and how it struggles to maintain balance or “homeostasis” in a family living with mental illness, one can understand why some of the symptoms surface, why some of the burdens initiate, and in doing so, one can have a better understanding of the family and find more effective interventions to help such families.

In summary, while interviewing the family caregivers, these five different concepts were used to understand the dynamics of the family when dealing with the mental illness. By being cognizant of these five concepts and by applying them in the analysis of the findings, one can gain a deeper understanding of the meaning behind the individuals’ words and actions.

### **Application of Systems Theory to Family Caregivers of the Mentally Ill**

In general, most of the research on the mentally ill is focused at understanding the mentally ill person. In addition, the interventions and programs aimed at dealing with the mentally ill are mainly focused on assisting one individual at a time (Stuart & Sundeen, 1995). The intervention is either directed toward the ill patient or the ailing family member. It fails to look at the family as a whole. The family is a system and to holistically assist the mentally ill, it is imperative to understand those who are providing support and guidance on a daily basis.

When individuals with mental illness are unable to work or care for themselves, it is the family that has the added responsibility of taking care of them. Thus, to assist mentally

ill individuals, mental health providers need to focus on the entire family unit (Suresky et al., 2008). With family systems theory, one looks at the wholeness of the family because of the belief that the issues family members experience impact the family as a whole. Applying the concept of circular causality, one can conclude that in such a family, each family member would feel burdened by the caretaking role and that each person's feeling of burden would affect every other family member in a circular repetitive manner.

According to Gilbert (2006) a system looks at the emotional process among family members because the family is seen as a single unit. By understanding this concept, one can conclude that mental illness in the family affects the relationships among all the individuals in the family. Thus, in looking for any kind of mental health care, it is important to look at the family as a whole.

Fujino and Okamura (2009) conducted a study with the purpose of identifying the factors that affect the sense of burden felt by the family caregivers for patients who had a mental illness and were living at home in Japan. The researchers used a cross-sectional method. They conducted a study with 30 patients and their 30 family caregivers. The participants were selected from a rural psychiatric hospital in Japan. All patients were receiving home nursing care. The home service nurse assisted the researchers with contacting the interested families, getting informed consent forms signed, and accompanying the principal investigator to the patients' homes. All patients and their family caregivers filled out a questionnaire and were interviewed for 30 to 40 minutes. The researchers then conducted a multiple-regression analysis. The independent variable was the sense of burden for the families involved. Family systems theory was used as theoretical framework because the researchers perceived that the burden felt by the family caregivers as well as the factors

associated with the burden, affected the family as a whole. They found that the patients' satisfaction with their day-to-day lives and their ability to perform tasks were related to the sense of burden that the caregivers felt. The task in this case was the ability of the patients with mental illness to carry out necessary daily tasks of survival such as utilizing a skill that they had learned. If the mentally ill patients were able to accomplish the tasks necessary for their day-to-day living (such as housework) the sense of burden experienced by the family caregivers diminished (Fujino & Okamura, 2009). Fujino and Okamura (2009) also found that there was a relationship with the sense of burden felt by the family caregivers and with their attitude about life that the researchers labeled as "life is worth living" (p.137). "Life is worth living" as used by the researchers, was a synonym for having a purpose in life. The researchers found that if family caregivers had an increased life purpose the burden that they felt diminished. Fujino and Okamura (2009) also found that "family care that concentrates on the relationships and interactions of the family members by using family systems theory with the combination of conducting assessment and care for the individual family members is critical in reducing the sense of burden felt by the caregivers" (p.137).

### **Stages of Bipolar Disorder and Schizophrenia**

When looking at psychiatric disorders, primary prevention of mental illness has not been a possibility. For this reason, the focus has shifted to secondary intervention which is to recognize the earliest stages of the mental illness and to intervene appropriately (Berk et al., 2007).

The idea of recognizing the initial stage of the mental illness came from the management of schizophrenia by recognizing first episodes of psychosis. After the first episode of psychosis in schizophrenia, scientists discovered that there was hippocampal loss

and ventricular dilatation which necessitated the need to prevent another psychotic episode. Hence in the case of schizophrenia, secondary prevention was of great value (Velakoulis et al., 2006). However, with bipolar disorder, the neurostructural changes are not present and only become evident after the recurrence of the manic episodes (Strakowski et al., 1998). Due to the apparent course of many psychiatric illnesses, looking at mental illness as a disease with a stage has become a practical method of dealing with mental illness in the field of psychiatry. A disease with a stage implies that individuals typically progress through a number of steps and that each step has its own qualities and implications for treatment (Berk et al., 2007).

### **Definition of Bipolar Disorder and its Stages**

Bipolar disorder encompasses episodes of dysfunctional mood potentially including major depressive episodes, manic episodes, hypomanic episodes, and mixed episodes. They are often separated by periods of relatively normal mood (American Psychiatric Association, 2000). The depressive phase of bipolar disorder closely resembles the depression associated with a major depressive disorder but may have some differences. Bipolar disorder is more likely to include psychotic thinking and the depression associated with bipolar disorder is more severe than the one in major depressive disorder.

A manic episode is defined as one having a persistently elevated, expansive, or irritable mood lasting for at least 1 week. A manic episode is connected with bipolar 1. A manic episode is naturally severe and causes impairment in many areas connected to person's social and occupational functioning. People going through a manic episode tend to view themselves as being powerful or have ideas of being a great success. They may have racing thoughts, have an increase in activities, and become excessive in pleasure seeking activities

such as excess spending or over exercising. They may not regard the risks associated with their behaviors and may become hostile if challenged. Their impulse control becomes poor, and they can become easily distracted. A hypomanic episode characterizes bipolar 2. A hypomanic episode resembles a manic episode in terms of symptoms and accompanying moods. The difference between mania and hypomania is that in hypomania, the duration of the symptoms is around 4 days whereas in mania it usually last about 7 days. In addition, hypomania is less severe and does not cause significant impairment in functioning.

According to Berk et al. (2007), bipolar disorder is a progressive illness. The concept of clinical staging is entrenched in medicine and forms the foundation for understanding of illnesses such as cancer and many others. Due to the apparent course of many psychiatric illnesses, staging is a reasonable concept to apply to psychiatric disorders. Berk et al. (2007) described a staging model for bipolar disorder. The following section describes the model.

**Stage 0.** At this stage, the risk factors for having bipolar disorder may be present but the individual has not manifested any of the overt symptoms. Some of the risks predisposing someone to bipolar illness are genetic. According to the American Psychiatric Association (2000), first-degree biological relatives of individuals with bipolar disorder 1 have an elevated rate of bipolar 1 disorder (about 4% -24%) and for those with bipolar 2 disorders; the rate is (1% -5%). Individuals who have a mood disorder in their first-degree biological relative are more likely to experience an early onset of the illness. Other associated risks for developing bipolar disorder are pregnancy and obstetric complications, childhood psychological and physical abuse, and substance abuse. At this stage, the interventions are limited because the illness has not manifested itself.

**Stage 1.** This stage is called the prodromal stage. The prodromal stage refers to the year before the illness starts to become evident. In medical terms prodrome is a description of the early symptoms of an illness before the typical symptom of the illness appears (Veague, 2007). The prodromal stage is subdivided into 1a and 1 b. 1a represents a stage where the symptoms are mild and difficult to identify. 1 b is composed of some recognizable prodromal symptoms. At this stage, there are some signs of bipolar disorder such as generalized distress but in general, the symptoms lack specificity, especially in adolescents. Therefore, therapeutic interventions continue to be broad and not necessarily focused on bipolar disorder treatment. More research is needed to predict the course of mental illness at this stage and at the present, evidence is still insufficient for tailored treatment (Berk et al., 2007).

**Stage 2.** This is the stage known for its first episode of mania and this is the time of the onset of the illness. The presence of mania at this stage is mandatory for a DSM IV diagnosis (American Psychiatric Association, 2000). It is at this point that the distinction between the different types of bipolar disorder is made. For example, the diagnosis of bipolar I, at stage 2 is effectively indicated by a first episode of mania. Therefore, during this stage, once the illness is correctly diagnosed, the main purpose of treatment becomes to prevent further episodes of mania.

**Stage 3.** This stage is known as the stage of recurrence, and is the stage where most research into bipolar disorder has been conducted to date. This stage is further subdivided into stage 3a, 3 b, and 3 c. Sub-stage 3 a signals the recurrence of subthreshold symptoms. At sub-stage 3b, threshold symptoms have occurred. Sub-stage 3c is marked by repeated

persistent relapses or by the rapid-cycling of the disorder. Thus, each subdivision of this stage differentiates the degree of the symptoms experienced by the individual.

**Stage 4.** At this stage, treatments that are administered are more aggressive. It is common to administer clozapine or a combination of strategies such as ECT (electroconvulsive therapy). ECT or electroshock therapy is a short term treatment for severe manic or depressive episodes especially when they involve a serious risk or suicidal or psychotic symptoms. It is also used when medicines seem to be ineffective. ECT is effective in about 75% of patients. It is used when it is unsafe to wait for the drugs to show their effect. (n.d. retrieved on 10/26/2013)

The staging model is common in the field of medicine because it guides prognosis and therapy according to the stage of the illness (Berk et al., 2007). The staging model implies that earlier stages of an illness have better prognosis and that response to any treatment is more effective when introduced early in the course of the illness (Berk et al., 2007). Hence, a stage model of bipolar disorder can prevent further damage and improve the prognosis of the illness.

In general there has been a delay in diagnosis at a global level for bipolar disorder. In some cases the mean for the delay to diagnosis was 12.5 years. The delay in diagnosis was even longer for those with an onset before the age of 15 with a mean of 16.3 years to get the diagnosis. For those over 35, the waiting period to get the proper diagnosis was much shorter with a mean of 2.7 years (Berk et al., 2007). However, many times the person who is bipolar is misdiagnosed as either having unipolar depression or sometimes borderline personality and substance abuse (M. Berk et al., .2007). Misdiagnosis presents clear risks especially because

of using antidepressants for manic switching and cycle acceleration which is common in bipolar disorder (Post et al., 2001).

According to Reinares et al. (2010), underdiagnosis or misdiagnosis happens in bipolar disorder which creates a delay in patients receiving proper treatment. When treatment is delayed, patients may face more cognitive impairment, family struggles, and deterioration of social and occupational functioning. In some cases, it can increase the risk of substance abuse and suicide.

Reinares et al. (2010) conducted a study on the impact of looking at bipolar disorder as a disorder with stages when planning family psychoeducation. The purpose of the study was to assess whether a staging model in bipolar disorder had an impact on patient's response to psychoeducation delivered to the family caregivers. The subjects were 113 bipolar 1 and bipolar 2 patients. These patients participated in a randomized controlled trial on the prophylactic efficacy of administering psychoeducational training to the family caregivers. There were two different groups called stage 1 and stage 2. Stage 1 included the caregivers for the patients with bipolar disorder who had no functional or clinical impairment and were at the beginning stage of bipolar disorder. Stage 2 included the caregivers for patients who were at more advanced stages of the mental illness and had functional or clinical impairments. A post-hoc analysis was conducted. The results indicated that the patients at stage 1 benefited from their caregivers' psychoeducational training by having a longer time before recurrence. In other words, in the patients at stage 1 the time between another relapse and another psychotic episode was longer. For the patients at stage 2 there was no change in the patient's relapse time. This study highlighted the importance of early intervention in bipolar disorder. It also stressed the need to tailor the intervention to the stage

of the illness. The researchers in this study concluded that psychological interventions together with pharmacological treatment can improve the outcome of bipolar disorder (Reinares et al., 2010).

### **Definition of Schizophrenia and its Stages**

Schizophrenia is a serious mental illness impacting the patients, the caregivers, and society. Schizophrenia is a neurodevelopmental disorder and has different phases (Lee, McGlashan, & Woods, 2005). Veague (2007) identified three stages of schizophrenia. They are the Prodromal stage, the Acute stage, and the Residual stage.

**Prodromal stage.** The individuals at this stage isolate themselves, start losing motivation in their daily routines, and at times their speech patterns start to change. This stage can start in early childhood and often the family caregivers are the ones who start to notice the odd behaviors of their mentally ill relative. The family members start noticing the odd behaviors even before the diagnosis of mental illness. However, many of the behaviors at the prodromal stage are also within the normal range of experience.

**Acute stage.** The Acute stage also called the Psychotic phase (Lee et al., 2005), is the time when the individual starts experiencing psychotic symptoms such as hallucinations, delusions, or grossly uncontrolled behavior. This phase is also labeled as the active phase. Doctors cannot diagnose schizophrenia until the active phase. This is the time when the individual is placed on anti-psychotic medications which are designed to control the psychotic symptoms. At this stage one can see the full impact of the illness. 75% of persons with the onset of schizophrenia are between 16 and 25. Usually an onset after 40 is rare.

**Residual stage.** This stage is also known as the Recovery stage. At this stage, the patient starts to become more stable after being treated. This stage is similar to the first stage

because people may not be psychotic because of being medicated but they may continue to have odd beliefs and may also have negative symptoms such as a lack of emotional expression, having low energy, and cognitive dysfunction.

The range of impact of schizophrenia and residual symptoms is varied with some patients experiencing remission and being asymptomatic to others who experience anxiety or depression and others with low level interference from residual positive symptoms. It is estimated that following the first psychotic episode, 90% of patients experience remission after one year of treatment, although only 30% of those patients will be functioning well. Patients who relapse or attempt suicide may require hospitalization.

The period lasting five years following the first psychotic episode is called the early course of schizophrenia. According to the APA, during this time up to 80% of patients will have a relapse of a psychotic episode headed by a prodromal period of nonspecific symptoms and emotional disturbance and then followed by the onset of the psychotic episode. This progression typically occurs over a four week period. Approximately 5-10 years after onset, most patients experience a plateau in the illness as well at their level of functioning. The extent of family and social support plays an important role in influencing the course of the illness and prevention of relapse (N.D. retrieved on 10/19/2013)

In summary, when dealing with mental illness, there are many obstacles that providers face before appropriate treatment is administered. For instance, before treatment can be administered, providers feel that it is important to accept the mental illness and adhere to treatment. For this reason, appropriate psychosocial interventions become a necessary ingredient for treatment and the need for creating interventions targeting the different stages of the mental illness can provide the mentally ill with a better outcome. By providing the

needed intervention early in the progression of the disease, the prognosis of serious mental illness can be dramatically improved. (Berk et al., 2007).

Consequently, the first episode of a mental illness is a crucial time where providers can start early interventions in order to protect the individuals from further damage that results from the progression of the mental illness. Each stage is different and treatment and interventions can be tailored for each specific stage (Berk, Hallam, & McGorry, 2007). Accordingly, since information about preventing a mental illness is limited, psychiatry is more focused on preventing further damage after the first psychotic episode which is the time of the onset of the mental illness. During the first psychotic episode in schizophrenia, damage to the brain has already occurred. In bipolar disorder, damage is not evident until recurrent psychotic episodes. For this reason, preventing psychotic episodes is crucial in both disorders in order to prevent further damage. Medication helps stabilize patients. In addition to medication, psychosocial interventions prevent patients from quick relapse. Research on patients with bipolar disorder and their family caregivers shows that a combination of pharmacological and psychoeducational intervention for the family caregivers is effective in delaying recurrence of the mental illness if the patients were at the beginning stages of bipolar disorder (Reinares et al., 2010).

### **Summary**

The literature reviewed herein along with the researcher's personal interest inspired this study. The literature review began with a historical analysis of deinstitutionalization which was responsible for the movement of the mentally ill population being discharged into community settings once they became stable on anti-psychotic medications. Because of this movement, more than 4 million American families are entrusted with the caregiving of

mentally ill relatives who are living at home. In order to understand the lived experiences of family caregivers of the mentally ill, an examination of family systems theory and its application in several studies dealing with the lived experiences of family caregivers of the mentally ill was presented. In addition, other relevant studies about family caregivers and their lived experiences with their relatives' mental illness were included. Included in this chapter was a definition of bipolar disorder and schizophrenia including the descriptions of the corresponding stages.

In order to be effective, treatment as well as the intervention created for the mentally ill and their family caregivers should target the different stages of the mental illness. In addition, intervention for bipolar disorder and schizophrenia should be administered early in the course of the disorder. After the first signs of psychosis, the main focus for treatment for both disorders is to prevent another recurrence. Research by Reinares et al. (2010) confirmed that a combination of pharmacological and psychoeducational interventions for the family caregivers is shown to be effective in delaying recurrence of the mental illness.

### **Chapter 3: Methodology**

The following chapter covers the design of this study, including the methodological framework and specific research methods that were used to collect and analyze data.

Included in this methodological plan is a discussion of ethical considerations which may limit this type of study. This methodology was guided by the research question. To review, the research question was: What are the lived experiences of the family caregivers of a relative with the diagnosis of schizophrenia or bi-polar disorder through the different stages of the mental illness?

#### **Methodological Framework/Narrative Research**

Narrative inquiry was used as the primary research methodology. According to Camic, Rhodes, and Yardley (2003), narratives shape our reality and the way we see ourselves. The central reason that draws researchers to narrative inquiry is the idea that stories and storytelling create meaning in our lives (Mayan, 2009). Mayan (2009) also believes that narratives can be used as a tool for understanding the larger social experiences of any individual. According to Camic, Rhodes, and Yardley (2003), narratives are connected with the way we create our personal identities through the stories we tell to each other. These researchers hold that narratives are about our social interactions and that they shape the world and the way we see ourselves. In this study, the narratives from the family members provided a vehicle to look at the relationships the individuals had with each other.

In general, narrative analysis enables us to interpret the stories of the individuals (Brunner, 1990). Thus in interpreting the way that individuals describe their experiences, we describe what they are describing. Riessman (1993) believes that narrativization not only describes past experiences but also describes the way that individuals understand those

experiences and what meaning they give to those experiences. In describing narrative analysis Riessman adds: “because the approach gives prominence to human agency and imagination, it is well suited for studies of subjectivity and identity” (Riessman, 1993, p. 5). Narratives can help one decipher the meaning that individuals give to their experiences. By studying the meaning of the individuals’ experiences one can understand their subjective experiences, as well as understand their identity.

In understanding a person’s story, a researcher has to first understand the process of narrating a story. Riessman (1993) illustrates the process of story -telling by breaking the process into five steps. They are: (1) attending, (2) telling, (3) transcribing, (4) analyzing, and (5) reading (Riessman, 1993). This process helps the researcher understand how one represents an experience, which is useful to understand how the storyteller recounts an experience and also how the researcher listening to a story describes the experience. Attending refers to the act of attending to an experience such as reflecting on something or becoming aware of the phenomenon to be studied which then makes it meaningful. Thus a researcher will first have to become aware of what is to be studied. The second step is called telling. Telling refers to the “performance of a personal narrative” (Reissman, 1993, p. 9) which would be when a person is talking and stating his or her story. In telling, the individual tells and recounts the experience into narrative form. At that point the individual tells a story as an insider and someone who is part of that story. Reissman believes that the individual telling the story is also creating an image of the self. At the same time the individual is thinking about how he or she wants to be known by the listener. The process of telling happens each time the subject being studied tells a story and each time the researcher creates a narrative about the story. In telling, individuals have a certain way of looking at

themselves and at the same time are aware of the image they are creating of themselves. By the same token, the researcher also has a self-image of himself or herself when telling the story. The third step in representing experience is called transcribing the experience. Reissman sees this process as being “incomplete, partial, and selective” (Reissman, 1993, p. 11). Transcribing the experience is a process that requires interpretation and the transcriber interprets the experience according to his or her own frame or lens. Thus as researchers, our transcriptions are incomplete and subjective. However, Reissman defends the subjectivity of the transcription by stating that “different transcription conventions lead to and support different interpretations and ideological positions, and they ultimately create different worlds” (Reissman, 1993, p. 13). Hence different interpretations and different ideological positions according to Reissman, is part of what research intends to do, to make “different worlds” and accordingly, help us understand the subjectivity of the human experience. The fourth step, which is analyzing the experience, is when a researcher finally analyzes the transcript. The analysis comes from analyzing the experiences and looking for a way to understand them. The fifth and final stage of this process is called reading experience. At this stage one reads the final report. Reissman (1993) adds that in reading, the work can provide different meanings to different people. Therefore, even in reading a report of something described by the researcher, the reader’s own frame of reference affects the meaning for that person.

Riesman’s five steps in describing the lived experiences of individuals gives the researcher an inclusive understanding of the ways an experience is processed, narrated, and recorded (Reissman, 1993). Each person listening to any story goes through different stages of sifting the information according to one’s own frame of reference. Hence, one has to

provide the context of the experiences as well as the researcher's own background for the readers. In looking at this aspect Reissman writes, "Written texts are created within, and against, particular traditions and audiences, and these contexts can be brought to bear by the reader" (Reissman, 1993, p. 15).

This study described the lived experiences, state of mind, and perceptions of the families caring for a mentally ill relative. Narrative analyses of the caregivers' life histories provided the vehicle to understand the caregivers' lived experiences. The narratives also served as a vehicle to look at the relationships of the individuals with each other. Thus, the life histories provided insight into the caregivers' own constructions of the social and mental realities that they faced.

In particular, another aim of this study was to find out if there was a difference in the way families constructed their stories before, during, and after the onset or diagnosis of the mental illness. This type of chronological sequence in telling life histories was formulated to be able to understand the family caregivers' lived experiences throughout the different stages of the mental illness. Separating the questions into three different stages facilitated the understanding of the different areas that impacted the families' lives as a result of their relative's mental illness. In each stage, they talked about the issues pertaining to the mental illness, its diagnosis, and its impact at each different time in their lives.

Moreover, by sharing their stories, the participants gained a central role, which was a powerful tool because it gave them a chance to tell their stories from their own perspectives. Telling their life stories also provided them with a feeling of being in control because they were the storytellers and the main characters at the time they were telling their stories.

## **Methods of Data Collection**

**Life Histories.** The primary method of data collection was life history interviews. The life history interviews were used to create a narrative of the caregivers' lived experiences with the mental illness of a relative. Life history interviews are taken from individuals who recount their life and their own experiences (Glesne, 2010). The interviews were intended to look at the lived experiences of the caregivers in many different areas of their lives, such as the impact on their relationships with each other and society, their finances, their relationships with the medical community, their feelings about being stigmatized because of their relative's mental illness, their own emotional health, and their methods of coping with the illness as well as their methods of taking care of themselves. The interviews that were conducted for this study provided information about each family caregiver's life and his or her experiences with their mentally ill relative. Each person's story was unique and took the reader to the participant's inner world and their struggles with the mentally ill relative's mental illness. The stories were related with honesty and rich details which provided an in-depth look at the family caregivers' lives.

In describing methods of gathering data for narratives, Clandilin & Connely (2000), recommended collecting data from a large variety of sources. To this end, the aim was to better understand the participants' inner realities and the meaning of their words by asking the participants for artifacts and/or photographs that held special meaning for them as caregivers of their mentally ill relative. These objects provided the researcher an emic view of the caregivers' lived experiences. The emic view "relates to or involves analysis of cultural phenomenon from the perspective of one who participates in the culture being studied" (n.d., Merriam-Webster's online dictionary, 11<sup>th</sup> Ed). The artifacts and photographs

from the caregivers helped to bring up other experiences related to the mental illness that had not come up during the interviews. Family caregivers brought photographs from the time when the mentally ill relative was “normal” and did not show any of the symptomatic behaviors that came about at the onset of the illness. All the caregivers brought a photograph that gave the researcher a glimpse of the families’ past. One of the caregivers also brought in an artifact (a silk screen painting that the family caregiver had made while in college) in addition to the photograph. The artifacts and the photographs painted a more complete picture of the caregivers’ life histories.

**Sample.** The participants for this study were a purposive sample (Mayan, 2010). The criteria for selecting them were the following:

- 1) The families had at least one family member who was diagnosed with the mental illness of either schizophrenia or bipolar disorder.
- 2) The caregiver or caregivers were adults and were over 18 years old.

The participants were recruited from mental health agencies that provide out-patient mental health services for the mentally ill and their families. Two agencies participated. The directors of the agencies were contacted and posters describing the study were posted at the agencies. In addition, a letter describing the study as well as a copy of the poster describing the study was placed on the agencies’ list-serv via the Internet and E-mail. The mental health providers then recruited the potential participants. The principal investigator was contacted by the interested volunteers who called her at the telephone number provided on the posters. A total of six families contacted the principal investigator. After the initial interview, only 4 families were selected for this study. The other two families were not selected because they did not fit all the criteria for the study. One caregiver per family was interviewed in three of

the four families. In one of the families two caregivers were interviewed. A total of 5 caregivers were interviewed. The caregivers in each family signed a consent form. As stated previously, the primary method of data collection was life history interviews.

**Life history interviews.** To gather data on the life histories of the families, semi-structured interviews with each family caregiver were conducted. Creswell (2007) advises the researcher to use open-ended research questions during the interviewing process. Creswell also adds that researchers should shape the questions after further investigation because the questions will change during the process of the study with added understanding of the issue. Therefore, the original questions to the participants paved the way for further questions.

According to Camic, Rhodes, & Yardley (2003), the researcher's role as an interviewer in a narrative study is to encourage the participants to tell their stories. The authors also add that the researcher has to be empathic and supportive to the participants who need to feel that their stories are valued. The interviews were conducted at the family caregivers' homes which were safe and secure environments for them. The interviewer for this study was empathic and sensitive to any issues and concerns that came up as a result of talking about their relative's mental illness. Being empathic and supportive is especially important when dealing with people who live with mental illness because family caregivers may have suffered as a result of the stress and burden, as well as the stigma associated with the mental illness and a supportive style can enhance their feelings of being heard and of being accepted.

Semi-structured interviews regarding family caregivers' lived experiences with the mental illness were conducted. The interviewer asked each family caregiver to talk about his

or her life and his or her day-to-day experience of living with the mentally ill relative. In addition, open-ended questions were incorporated during the interviews in order to clarify the emic experiences of the caregivers or to elaborate on the different areas pertaining to the caregiver's life throughout the progression of the mental illness. The questions were also designed to collect information about their experiences from three different times in their lives, the time before the diagnosis of the mental illness, the time during the diagnosis of the mental illness, and the time after the diagnosis of the mental illness.

The preliminary interview questions were developed by using a chronological sequence of qualitative analysis as prescribed by Creswell (2007). The main objective of a chronological sketch is to look for life-course stages or experiences such as childhood, marriage, employment, place of residence, siblings, etc. (Creswell, 2007). Life-course stages mark important times in a person's life, and for the caregivers, the mental illness of a relative is an important life-course.

The interview questions were divided into three main categories. They were as follows: 1) Life before the onset and diagnosis of the illness, 2) Life during the onset and diagnosis of the illness, and 3) Life after the onset and diagnosis of the illness. Under each of these categories, were 6 sub questions, concerning: (a) the relationships of the family members with each other (b) the family's relationship with society including stigma because of the mental illness, (c), the family's finances, (d) the family's emotional health; (e) help from mental health providers, (f) the family's coping skills and its methods of self-care (see Appendix B for a list of these questions).

Three separate informal interviews were conducted. The objective of the first interview was to gather information about the participants' life histories. During the first

interview, the interviewer started to collect information about the family caregivers' lives and their day-to-day experiences as caregivers for their mentally ill relative. A protocol sheet is attached with a list of the questions (See Appendix B for the sample interview protocol).

Each interview lasted between one to two hours. Data from the narratives of the participants' preliminary interviews were transcribed and analyzed. The objective of the second interview was to continue gathering information about the participants' life histories. For this purpose, the participants were asked to bring a photograph and/or artifact that held a special meaning for them. The photographs and/or artifact reflected their experiences as caregivers for their mentally ill relative. During the second interview, the interviewer asked the participants to relay the meaning that the photographs and/or artifact held from them. Their responses to the questions were included as data in the life history narratives. During the second interview, another objective was to share preliminary analyses of the first interviews with the participants to ensure that the data collected up to that date reflected the experiences of family caregivers. The participants' responses to the preliminary analyses were also integrated as data for subsequent analyses. The objective of the third interview was to share the draft of the analysis of data with the participants for member checking purposes (Mayan, 2009). During the third interview, the participants were asked to look at the draft and state if preliminary analyses of the narratives reflected their life histories. Their responses were included as data for subsequent analyses of the participants' life histories.

All the interviews were conducted face-to-face. All the interviews were tape-recorded using an interview protocol sheet (Creswell, 2007). This protocol sheet contained a header with the following information: (1) time of interview, (2) date, (3) place of the interview, (4) name of the researcher, (5) the interviewee's pseudonym, and (6) a brief

description of the interview outcome. The main body of the protocol included the questions asked (See Appendix A for the sample interview protocol). All the interviews were transcribed and stored on a USB drive in a private location. The data collection and transcription phase lasted about three months.

**Other data.** The participants had the choice to either submit a photograph and/or artifact that held special meaning for them. Each caregiver brought in a photograph of his or her life with the mentally ill relative. In addition to the photograph, one caregiver chose to bring in an artifact which was a silk screen painting. To analyze these data, the participants were asked what the photographs and the objects meant for them. Data taken from the interviews about the objects and artifacts were included in the participants' life histories and analyzed as narrative texts.

### **Method of Data Analysis**

In order to conduct narrative inquiry, a deductive and an inductive method of data analysis was used. A deductive process is one where the researcher has a pre-existing framework or theory and a hypothesis is tested within that framework. An inductive process on the other hand, is one where the researcher starts with individual ideas and, an overall theory, or story, or description is created (Mayan, 2009). The researcher used family systems theory as the framework for deductive reasoning. Inductive reasoning was incorporated to enable the researcher to discover emic themes within the data that came from the participants' own words.

Data that is collected in a narrative study has to be understood and analyzed for the stories that the individuals have to relate with a chronology of unfolding events, and important turning points as well as epiphanies (Creswell, 2007). The sequence of steps that

were taken in conducting the analysis were: “1) creating and organizing files for data; 2) reading through text, making notes in the margins, and starting to form initial codes; 3) describing the story set of experiences and placing it in chronological format; 4) identifying stories, locating epiphanies, and identifying contextual materials; 5) interpreting the larger meaning of the story; and, 6) representing the narration by focusing on the processes, theories, and main features of the life “ (Creswell, 2007, p. 156).

In this system of coding, *in vivo* coding was used, which involved labeling sections of text with the exact words used by the participants (Creswell, 2007) as well as open coding, which involved relating concepts with each other to “break the data apart and define concepts for blocks of raw data” (Corbin & Strauss, 2008, p. 198). Five different concepts from family systems theory were used: (1) Homeostasis and circular causality, (2) Emotional triangles, (3) The identified patient, (4) The differentiation of self, and (5) The extended family. These concepts defined common recurring themes which were used for data analysis.

Each person had his or her own way of looking at their lived experiences and when telling their stories, individuals shared a story that they constructed based on their own reality. In looking at the way the individuals described themselves and their lived experiences with the mental illness, the researcher was cognizant of the role that all participants had in life histories. The person being interviewed was selected because that person was the main caregiver for the mentally ill relative. The researcher looked at life histories from their perspectives and then, in analysis, the story was told by combining the person’s story and by telling the story from yet another perspective. In retelling the story one has to be cognizant of the image that the person is portraying (Reissman, 1993).

The participants were asked to talk about what the objects (photographs and/or artifact) meant for them in order to understand the meaning that each item held for them. After gathering the meaning that the artifacts and the photographs held for the participants, data collected was analyzed as narrative texts. The narratives about the photographs and or/artifacts were analyzed using the same six steps of data analysis, as described by Creswell (2007).

### **Limitations**

One of the limitations of this study was that it did not reflect all mental illnesses and was limited to only the ones that were part of this study. In addition, this study was conducted in a city in the southwest and may be limited to the cultural and social frameworks that exist within that geographical location. On the other hand, since most of the family caregivers had migrated to the southwest as young adults and had lived in different areas of the United States prior to coming to the southwest, this study cannot represent only residents of the particular city where they were residing. Only one family caregiver in this study was originally born and raised in the southwest. Three of the family caregivers were originally from the east coast and one family caregiver was an immigrant from Russia. More research targeting the implications of the geographical area where the family resides would enhance the understanding of how culture and the environment influence the family caregivers' lived experiences. Another limitation of this study was that this was a small sample and a qualitative inquiry, which cannot be generalized to the experiences of all families who have a mentally ill family member diagnosed with schizophrenia and bipolar disorder. This was an in-depth narrative inquiry. The lived experience of each family caregiver represents a person's subjective world.

In addition, this research was focused on discovering the experiences of family caregivers who were directly involved with the caregiving of their mentally ill relative. The lived experiences of the other family members who were not fully involved in the caregiving process were not explored. Perceptions of the other family members including the perceptions of the mentally ill individuals may add another dimension to the study of the burdens experienced by such families. This may assist in giving a wider perspective of the family's experience while living with their mentally ill relatives.

### **Trustworthiness**

The trademarks of a trustworthy study are credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Credibility is about accuracy. It is about looking at how well the findings portray the phenomenon being studied. Transferability is about how well the findings can be generalized to other settings. Dependability asks the following question: how well are the findings able to be reproduced by another researcher? Confirmability is about how free the research is from researcher's bias.

The credibility criterion according to Lincoln and Guba (1985) can be met by implementing member checking which they believed to be the most imperative technique for establishing credibility. To establish credibility, the findings were shared with the participants at the second meeting. This was important to ensure that the data gathered portrayed an accurate description of the participants' lived experiences. During the third and last meeting with the participants, the final analyses were also shared with the participants for purposes of member checking, to ensure representation of data and credibility. In addition, credibility was established by comparing the families' lives before the diagnosis or onset of the mental illness with their lives after the diagnosis or onset of the illness. This helped the

researcher to see how the family caregivers experienced events in a similar manner. Thus, by having a way of comparing the before and after experiences of the families, the researcher was able to see similar trends and was able to come up with some valuable conclusions. People reading the narrative stories may gain a deeper understanding of the participants' lives and may be able to identify with their experiences. In qualitative inquiry, credibility is also sought by checking that the story comes from the data (Mayan, 2010).

To ensure transferability of the data, a rich and thick description of the setting and the participants was provided. A rich and thick description can ensure transferability to other sites and situations (Mayan, 2010). "Thick" description is when a writer describes the experiences of the subjects with rich details (Creswell, 2007). With each participating family, details and descriptions about each family's background, and the context of their lived experiences were provided.

Confirmability was established by using triangulation and reflexivity. Triangulation is when a researcher uses multiple data, sources, methods, and/or theoretical schemes in order to validate data (Creswell, 2007). In this study, triangulation was established by using two different methods of collecting data. First, the researcher collected data through the semi-structured interviews. Second, data was collected from the narratives of the photographs and/or artifact (Creswell, 2007). In addition, the researcher used reflexivity in order to be aware of bias. For this purpose, the researcher was aware that her own experience as a therapist could color her perceptions. As a therapist, she was inclined to be the emotional healer and to assist individuals with solving a problem they may be having. In addition, if the interviewees knew that that she was a therapist, they may have been inclined to talk to her about their problems and expect her to conduct therapy sessions with them. The

researcher understood that the tendency to be a therapist on her part did exist, for it is something that was part of her experience as a professional mental health counselor. To avoid this situation, she structured the interview questions in a particular manner and did not conduct the interviews like a therapy session. The researcher used open-ended questions such as “tell me about the time you found out that your daughter was diagnosed with schizophrenia.” A therapist on the other hand may have asked: “how did you feel when you found out that your daughter had schizophrenia?” The researcher knew that she could easily fall back into the role as a therapist if the situation called for looking at someone’s emotional issues. For this reason, she remained constantly aware of the difference between the mind-set of a researcher and the mind-set of a therapist. However, being a therapist was also an asset because it helped the researcher to understand the subjects better and empathize with their situations. Being a therapist was an advantage when trying to get an *emic* view of someone else’s reality, which refers to seeing the world through the participant’s own point of view (Mayan, 2009). It also helped the researcher to better understand the typical life experiences of someone caring for a mentally ill relative.

In general, the researcher was cognizant of her own reactions to data in order to ensure that one’s pre-conceived notion or feelings were not clouding the findings. On the other hand, a researcher’s biases are always present in any type of study. Sometimes, it is the same bias and interest in the subject that drives one to strive for more and look for more; the key is not to undermine what is being learned in the process and at the same to sift out what is different, and valuable for the purpose of the study.

## **Summary**

This section began with a discussion of the methodological framework. Narrative inquiry was used. Face to face Life history interviews of the five family caregivers were conducted. Furthermore, the analysis incorporated data collected from the participants' interviews where they talked about the meaning that their photographs and/ or artifacts held for them.

This study used a purposive sample. Four families participated and five family caregivers were interviewed. The analysis of this study was conducted by using the six step method of analysis as described by Creswell (2007). In vivo and open coding was used to analyze data. Family systems theory was used as framework of analysis.

Finally, this chapter described trustworthiness. The researcher described the trademarks of a trustworthy study (Lincoln & Guba, 1985) and how they were used in this study.

## **Chapter 4: Findings**

In analyzing the life history interviews and the photographs or artifacts that the caregivers selected to bring to their second interviews several themes emerged. These themes helped to understand the lived experiences of the family caregivers as their relatives progressed through the different stages of the mental illness. The analysis of the interviews was conducted using family systems as a theoretical framework in order to understand the lived experiences of the family caregivers.

The analysis was conducted using five different concepts from family systems theory which were: (1) Homeostasis and circular causality, (2) Emotional triangles, (3) The identified patient, (4) The differentiation of self, and (5) The extended family. These concepts defined common recurring themes which were used for data analysis.

In analyzing the life histories, the photographs, and the artifact, the researcher divided the interview questions into three general areas which were chronological and were designed to gather data from three different times in the families' lives. They were the following: (1) Life before the onset and diagnosis of the mental illness, (2) Life during the onset and diagnosis of the mental illness, (3) Life after the onset and diagnosis of the mental illness.

Under each different chronological area of the findings, a synopsis of the concepts from systems theory is provided to facilitate the understanding of the deductive as well as the inductive method of analysis used in this study.

### **Emerging Themes**

In analyzing the responses from the life history interviews which included the analysis of data collected from the participants when they described artifacts, the following themes emerged: Under area one (Life before the onset and diagnosis of the Illness), the

themes were: (1) life in the good old days/sadness, and (2) the mentally ill relatives' good qualities and the loss of potential. Under section two (Life during the onset and diagnosis of the mental illness), the themes were: (1) denial and disbelief about the mental illness, (2) diagnosis and the medical community, and (3) finding the right combination of the medications for the mentally ill relative, (4) family's relationship with each other. This subtheme had two different sub-categories they were: (a) emotional health/ psychological distress, and (b) mentally ill relative's destructive or odd behaviors. Under area three (Life after the onset and diagnosis of the mental illness) the themes were: (1) the families' relationships with society and the community which included their embarrassment and stigma, (2) burden associated with lack of financial support, (3) the families' coping mechanisms which included their strategies for dealing with mental illness including their methods of self-care/gaining strength, and (4) their worries about their mentally ill relative's future.

### **Description of the Cases**

Four families were selected to participate in this study. For purposes of anonymity, the families' last names and family members' first names were changed. Families were named: The Chemova Family, the Taylor Family, the Duran Family, and the Lopez Family. One caregiver per family was interviewed, with the exception of the Taylor family where both the mother and the sister were interviewed. A total of five caregivers were interviewed for this study.

**Chemova family.** The Chemova family originally came from Russia. Initially, they lived in a major city on the east coast and moved to the southwest about 10 years ago. The main caregiver in this family is Natasha, the mother. She is the caregiver for her daughter

Violetta. Violetta's grandmother Vanya was also a caregiver for her until she moved to the United States when she was sixteen years old. Violetta is now 30 years old and was diagnosed with schizophrenia about 6 years ago. She does not have a job and is on disability. Natasha is in her early fifties and works as a civil engineer. Natasha has another son who lives in Russia with Violetta's father. He has been separated from his mother and his sister since the parents divorced which was over twenty years ago. Only Natasha and her daughter Violetta moved to the United States. They visit their family in Russia on a regular basis. Violetta's grandmother, her brother, and her father were not interviewed for this study because they have not been involved with Violetta's caretaking for several years and reside in Russia. However, Vanya's influence on both Natasha's and Violetta's lives was clear throughout the interviewing process for Vanya comes to visit Natasha and Violetta on a yearly basis and stays with them for a few weeks.

**Taylor family.** The Taylor family originally lived on the east coast but the family members relocated to different parts of the United States when the parents divorced about fifteen years ago. This family has two sons who have been diagnosed with a mental illness. The eldest son Mike is now 36 years old and is on disability. He was diagnosed with schizophrenia at the age of 22. However, the family caregivers who were interviewed believe that he also has a concurrent mood disorder. He can change from being calm to being enraged very quickly. The other son David is 27 years old and was diagnosed with bipolar disorder about 3 years ago. David does not have a job and is not getting any disability. The two caregivers who were interviewed from this family were the two men's mother Mimi and their sister Sally. Sally is married with 2 children and lives in the southwest. She is an art therapist. Sally has been a caregiver for her two brothers. Both of

her brothers have lived with her at one point in their lives. Her mother Mimi lives on the east coast, she is 64 years old, and works full-time as a medical assistant. Mimi's son David moved in with her when he was diagnosed with bipolar disorder. Mimi visits her daughter Sally during the holidays. Sally and Mimi were both interviewed in Sally's home in the southwest when Mimi was visiting Sally. When the parents were still together the whole family lived together. However, since the parents divorced which was over 15 years ago, Sally and Mimi have been the main caregivers for David and Mike. The father was not interviewed because he has not been with the family or involved in his two sons' caretaking for the past fifteen years. The father has started another family since his divorce from Mimi.

**Duran family.** The Duran family is a family with a father who was diagnosed with schizophrenia late in his life. His name is James. Before that, for many years the family was aware that James had a mental disorder but he was not properly diagnosed until the age of 70. The family lived on the east coast. James was a school teacher and graduated from Harvard. The mother was a housewife and did odd jobs to support the family. The caregiver who was interviewed for this study was their daughter Caroline who is now in her early fifties. Caroline is a psychotherapist and she moved to the southwest around 25 years ago. Caroline continued to be her father's caregiver even when she lived in another state. Each time there was a problem with her father they would contact Caroline. James was diagnosed with schizophrenia when he was hospitalized with Parkinson's disease. Once diagnosed, James was treated for mental illness as well as Parkinson's disease and moved to a nursing home. At that point, Caroline decided to have her father move to a nursing home in the southwest to be closer to her. For the last ten years of his life, from age 70 to age 80, Caroline took care of her father until his death. She lives with her children and her sister lives in another state. .

**Lopez family.** The Lopez family is headed by a father who was diagnosed with bipolar disorder about two years ago. All the members in this family were born and raised in the southwest. The father's name is Mico. Mico is on disability because of his mental illness and cannot keep a job for any length of time. He is 42 years old and his wife Emily is 35 years old. Mico and Emily got married around fifteen years ago but knew each other for twenty years because they lived in the same neighborhood and grew up in the same area. Emily's cousins were Mico's friends and she met him through them. She has been in his life since she was 15 years old and feels that she saw him become worse over the years until he was diagnosed with his mental illness. They have three children age 5, 7, and 12. Mico and Emily have been raising their three children with much struggle. Mico does not have a stable job and Emily has been ill with a tumor for the past two years. The family has had many difficulties living with Mico because of his mental illness. Mico has problems controlling his anger and when he gets angry, he becomes violent. Emily has tried to divorce Mico several times but gets back with him each time he promises to change his behaviors. Mico was recently diagnosed with bipolar disorder and began taking his medications. The medications have made a difference in Mico's mood according to Emily. Nevertheless, Emily is constantly ensuring that Mico gets proper treatment in order to control his anger and his aggressive behavior.

### **Life before the Onset and Diagnosis of the Mental Illness**

In general, life before the onset and diagnosis of the mental illness was better for the four families. In every family, the caregiver talked about the time when the mentally ill relative was not displaying symptoms of the illness. They all talked about how they missed that time. Before the diagnosis of the illness, the mentally ill relatives seemed to be

functioning well and were leading normal lives. The main topics that the caregivers recalled while describing the onset of the mental illness was connected to the following sub-themes: (1) the good old days/sadness, and (2) the mentally ill relative's good qualities /loss of potential.

**The good old days/sadness.** In the Chemova family Natasha mentioned that she had great hopes for her daughter because she brought her to the United States for “a better life.” Before the onset of the illness, Violetta was a college student, had a part-time job, and lived in her own home which was given to her by Natasha. While remembering “the good old days”, and the time before the onset of the illness, Natasha brought in a picture of her daughter and herself taken over 15 years ago at a restaurant. The picture was taken when Violetta was only 16 years old and when she first arrived to the United States from Russia. The family had gone out to celebrate Natasha's birthday at a fancy restaurant. The picture was taken by a family friend. Both mother and daughter look very happy for they are embracing each other and smiling. When talking about what the picture meant for her Natasha said:

At that time I was very happy because my daughter was here with me in the United States, after being apart for 5 years. I thought that I will give her all the commodities so that she can have a good life in America.

This brought tears to her eyes. She seemed sad as she recalled that time. At the time that the picture was taken, Natasha had made many plans for her daughter's future. When Natasha arrived to the United States around 16 years ago, she used to dream about the day when her daughter who was then in Russia would join her. She said: “I was hoping that Violetta would go to college, get married, and start a new life”. When Violetta finally came,

Natasha was proud of her own accomplishments and was feeling proud of her daughter. She had worked hard to bring her daughter to the United States and was happy. Then, when Violetta had a psychotic breakdown, Natasha felt that “all changed.” In remembering her family’s past and remembering Violetta before the onset of the illness Natasha said: “I remember how cute she was as a child, she was so beautiful and so bright.” Natasha talked about her daughter’s qualities in the past as if she no longer had them. In the past Natasha recalled that her family was united when they all lived in Russia. She was married, had two children and her life as she recalled was “better.” She is now living in the United States and even if her dream to come to America came true, her victory of “making it” in the United States was a bittersweet one for she discovered that her daughter was mentally ill. According to Natasha, the time before the onset of the illness was a time when there was family unity, and “things were not complicated.”

In the Taylor family, Sally also talked about “the good old days.” Before the onset of the illness, Sally thought that both of her brothers had a bright future ahead of them. She said that they were “bright and intelligent...my brother David was on a higher level than the rest of us.” The family lived on the east coast and was united. This was the time before the parents’ divorced and before Sally’s brothers were exhibiting any symptoms of mental illness. She remembers that before the onset of her brothers’ disorder, the family “had no problems” and that her brothers “had a normal development.”

Sally brought in a photograph of her family from the time when they lived on the east coast and when the family, was “happy.” She talked about that time with sadness. Sally chose a photograph of herself with her two brothers and her sister where all four siblings were under the age of 10. The picture was taken outdoors while they were vacationing with

their parents. The photograph depicts Sally, her sister Angie, and her two brothers Mike and David. Mike is holding David in his lap for David is a baby. The three older siblings were all smiling and all the children were very well dressed. She liked this picture for it depicted a time in her life when the family was united and when neither one of the brothers was displaying any signs of mental illness. Sally also equated that time in her life with family happiness for the family was still together and her parents were not yet divorced. Sally said that her father was part of a family business and stated: “We were rich and all together...we went to private schools and my parents belonged to country clubs. I do not see my father anymore and my family is dispersed throughout the United States.” Thus, Sally equated the time before the mental illness with happiness, being rich, and family unity.

In the Duran family, when describing the “good old days”, Caroline chose to bring a photograph of her wedding. She was standing in her backyard with her sister and her father on her wedding day. They were all well-dressed and smiling. She described that moment as the moment when she was very happy because her father was able to attend her wedding and was behaving “normally.” She said: “This was a risk that I took. I invited him to a small wedding in my backyard. He was delightful. This was one of my happiest memories of him.” The “risk that she took” most likely represented that she was not sure if her father would act “normally” on that day and she was happy that he did. Caroline also added that her wedding day was a “bittersweet” experience. When she described the photograph of her wedding day, she said that she felt happy that her father was there but at the same time she felt sad. She said:

This is happy; underneath of happy it was sad, sad that it was a hard road that my mother was not there, sad that we were always taking care of him. It is kind of bitter

sweet. In my heart, I felt the work of taking care of him. At the same time the love of seeing him there... there was always love.

Thus, when Caroline was talking about one of the happiest moments of her life with her father, she recalled some sadness. She was sad because her mother was not alive to see her get married and also because she felt that she always had to take care of her father. Perhaps she felt that by coming to her wedding, he was showing that he was “taking care of her” when in reality she was the one who always had to take care of her father.

In the Lopez family, in describing her feelings about the time when her husband was “better”, Emily brought in a picture of herself and her husband of her wedding day. The photograph depicted Emily and Mico standing at the church when they were getting married. Mico is dressed in a tuxedo and he looks happy, and hopeful. Emily looks radiant in her white wedding dress. Emily said that she felt sad looking at the photograph because she remembered that when she married Mico she was hoping that she would start a new life and start a family. She said: “during that time I was thinking that I was going to start a new life with Mico, and be happy....raise a family... before the marriage I used to be able to have fun with him.” The sadness came from the realization that things are not the way Emily would have liked them to be. In reality, Emily has had many difficulties in her marriage as a result of her husband’s mental illness and she has contemplated divorce many times. Emily does not rely on Mico’s emotional or financial support to raise her children and does not consider her life with Mico as a happy one. Emily reminisced about the way her husband used to be when they were both younger and when her husband was not exhibiting the symptoms of the illness.

**Mentally ill relatives' good qualities and loss of potential.** In the Chemova family, Natasha talked about how her daughter was accomplishing her goals just before the onset of the illness. In describing the time before the onset of the mental illness, Natasha said:

Violetta had finished high school and was attending college full time. She used to drive and I had bought her a car...she was getting a degree in Hotel Management... she also had a part-time job at a prominent hotel downtown where she was employed as a Management Intern...at that time, I had purchased a home for Violetta.

Before the psychotic breakdown, Violetta was becoming financially independent and was able to drive back and forth to school and to work. She is now unable to work and to drive and has become dependent on her mother. Natasha reminisces about the time when her daughter was able to take care of herself and was doing well with her career. In remembering that time Natasha stated: "I had so many hopes for her and now I feel like a failure."

In the Taylor family, Sally described her older brother Mike as a "talented singer and an amazing guitarist." When Mike was about 9 years old, he was selected to be in a famous boys' choir group. This was a very selective group and Mike attended a boarding school where he was able to participate in the choir and travel with them all around the world. Sally talked about this with pride for this was a very selective process and only the best could enroll. This was before the diagnosis of his mental illness and before he started to display the symptoms related to his disorder. Sally described her younger brother David as having been "very bright" before the onset of the mental illness. She mentioned that David was completing graduate school in the field of marketing before he has his psychotic breakdown. Likewise, when Sally's mother Mimi described her feelings about her two sons' lost potential

she said: “It was so sad.” She felt sad about the fact that David dropped out of graduate school when he was only a month away from completion. David was unable to finish his degree because of the onset of his mental illness which occurred right when he was completing his graduate degree. This was “a different David” according to Mimi, for the old David was “very intelligent” and “was completing his Masters’ degree at a very competitive college.” Mimi also felt sad about Mike because he could not pursue his musical career. Both Sally and her mother Mimi stated that they felt sad about Mike and David because they felt that the two men had talent and potential.

In the Duran family, Caroline was proud of the fact that her father had studied at Harvard and that he was a school teacher. Caroline’s father stopped working as a school teacher after he had his children and started to become delusional. Caroline talked about being impressed with her father’s background. While describing her father’s background and his personality she said that her father wanted to help the poor and that “he would give the shirt off his back”. She also said that she respected her father for being very religious and for believing strongly in God. She talked about the time when her father would be nice to her and her sister and would take them to the zoo on weekends. She said: “Sometimes he was so sweet and would take us to the bird sanctuary...he loved nature.”

In the Lopez family, Emily stated that her husband was an “amazing mechanic”. When Emily married Mico, she had hoped that he would be a good husband to her and a good father to her children. Before Mico started to display his anger and his violent behavior more frequently, there were times when he seemed calm and happy. That, according to Emily, was when he did not have three children and all the responsibilities of working and

taking care of them. Emily remembers being able to appreciate his personality and his love for her.

In summary, the caregivers talked about their feelings of sadness over losing their mentally ill relative to the illness. In general, the family members of the mentally ill usually experience grief and loss because of their relatives' mental illness (Rose & al, 2006). The feeling of loss that caregivers experience is one of losing their relative to mental illness. The caregivers remembered their life before the onset and the diagnosis of the mental illness as the "good old days." Most of the caregivers chose to bring photographs of their loved ones from a happier time before the onset of the illness or a time when the mentally ill relative was happy and not displaying the symptoms of the illness. They all chose a photograph of a time when the family was either celebrating something or happy about something and when they were together. Two of the caregivers selected a picture of their weddings. In telling their stories about the "good old days" all the caregivers showed feelings of sadness about the way the mentally ill relative used to be. The photographs in each case portrayed a glimpse of what was or what could have been. The family caregivers' sadness came from the fact that their loved one was no longer the same since the onset of the mental illness.

All the caregivers recalled the mentally ill person's "good qualities" and "loss of potential" with sadness. Some examples of the "good qualities" were: having been a good person who would give "his shirt off his back" to help someone (Duran family), or having been "fun to be with" (Lopez family). In addition, a common feeling among all the caregivers was the feeling of sadness due to the loss of potential. The loss of potential was due to the caregivers' feelings that the mentally ill person had not been able to use his or her potential due to the mental illness. Some examples of loss of potential were either having

been a good teacher who wanted to help the poor but had been unable to do so (The Duran family), or having been in a selective graduate program and not having been able to complete the program (The Taylor family), or having had a talent such as singing that had not been used and developed as a possible career (The Taylor family), and having been a good mechanic but having been unable to hold a job for a long time (The Lopez family). In each case, the mentally ill person did not pursue the area where he or she could have excelled or could have had as a career because of the symptoms associated with the mental illness.

Most of the family caregivers were feeling sad over the loss of potential and over the mentally ill person's inability to either keep a job or to develop a talent that they had. Family caregivers were sad because they could not help their mentally relative manage the illness and were unable to help them keep jobs or help them with developing their talents into a career. For example, Natasha and Mimi reminisced about the time when their children were successful and were getting prepared for a career in their field of study. Rose et al. (2006) found that when the level of mastery over the illness is low, caregivers' burden and stress was higher. The level of mastery was the level of mastery over the illness that family caregivers had with managing the mental illness. In the case of the two mothers in this study (Natasha and Mimi), the feelings of sadness over the loss of potential for their children may be connected to their feelings of not being able to do anything else to help their children from the loss of potential. Natasha blamed herself and felt like "a failure" and Mimi blamed her divorce for her son's inability to be successful in his field. In both cases, the mothers blamed themselves for not having been able to help their children.

### **Synopsis of Family Systems Theory in “life before the onset and diagnosis of the mental illness”**

In looking at family systems theory, the time before the onset of the mental illness for family caregivers was a time where the families did not seem to experience a lack of homeostasis or balance in the family unit. Family caregivers did not recall any major conflicts where one person, usually the family caregiver, took on the pressures of the family and became the identified patient (Bowen, 1994). Family caregivers did not experience many of the stressors, psychological distresses, or burdens associated with caregiving duties. Since the mentally ill family member had not started to display the symptomatic behaviors usually associated with the onset of the mental illness, there was an absence of emotional triangles or circular causality that usually come from a lack of balance in the family unit. The mentally ill relative was functioning within normal range. The family also did not seem to be experiencing any major financial difficulties or emotional conflicts. In addition, family caregivers did not need the help of the extended family to deal with their issues. However, the effect of the differentiation of self and the extended family affected all the stages of the illness. Bowen's concept of the differentiation of self and the extended family will be discussed in a separate section later on in this chapter.

### **Life during the Onset and Diagnosis of the Mental Illness**

The onset of the illness was a difficult time for the caregivers of the four families. During the onset of the illness, the family talked about the many changes that occurred in the family unit as a result of the behaviors of their mentally ill relative. One of the main reasons for psychological distress in caregivers is related to the mentally ill person's behaviors.

These disruptive behaviors add to the emotional and psychological distress experienced by family caregivers.

The main concerns during the onset and diagnosis of the mental illness were connected to the following sub- themes: (1) denial and disbelief about the mental illness; (2) diagnosis and the medical community/triggering event/hospitalization, (3) finding the right combination of medications for the mentally ill relative, (4) loss of balance, and (5) family's relationship. The sub-theme family's relationship included two sub-categories they were: (a) the family's emotional health/psychological distress, and, (b) mentally ill relative's destructive or odd behaviors.

**Denial and disbelief about the illness.** At the onset of the illness, the family members in three of the four families related a time when they were in denial or in disbelief about the possibility that their relative's behavior was an indication of a mental illness. In the Taylor family, the family was not aware that the father James had a mental illness until he was correctly diagnosed when he was seventy years old. However, throughout his life, his wife and his children suspected that he had some type of mental illness. However, according to Caroline "there were no doctors" and "people just did not talk about it then."

In the Chemova family, Natasha first believed that her daughter Violetta's behavior was caused by the fact that her father left the family and that she was depressed. Natasha also thought that her daughter would eventually outgrow those behaviors once she got older and more culturally assimilated to the American culture. In describing her daughter's behavior at the onset of the illness Natasha said:

At first, when she was acting this way, I thought that it was maybe a difference in culture because of moving to the United States from Russia...I was also thinking that

she was young and that she will get better, she will learn. I kept trying to help her with everything. She seemed to agree and understand but do the same things again... then, I would think what went wrong?

Thus, Natasha was looking for other reasons behind her daughter's "strange behaviors" attributing them to the difference in culture and to the fact that she was still young. Later on when her daughter's behavior did not change for the better, Natasha started to ask herself what had gone wrong in the upbringing of her daughter. She did not want to believe that it was mental illness at first because she was hoping that her daughter's behavior would eventually change. Natasha also talked about her own mother's denial regarding her daughter Violetta's illness. She said: "when they found out that she was mentally ill then my mother is still hoping that she stops taking the pills and that she will be better which I think is part of denial...because if she stops the pills, she will be what she was before and worse." Thus, Violetta's grandmother was hoping that Violetta would get better and that someday she would stop taking her medications. Natasha knows that if her daughter stops taking her medications, she will be delusional and have hallucinations. In addition, at one point Natasha believed that Violetta's friends "were bad people" and that Violetta was acting out because of them. She did not want to meet any of Violetta's friends and said that they "were not normal and were delinquents." However, Violetta continued to make friends with "the wrong people" over and over again. Natasha had triangulated the problems to Violetta's friends. Today, she realizes that it is Violetta who "makes the wrong choices" because "normal people do not want to be her friends."

Likewise, Mimi in the Taylor family also attributed her son David's psychotic behaviors as being the result of using too much Adderall because of having too much stress

in college. Mimi, in describing her son's use of Adderall and his psychotic breakdown mentioned: "it was too much pressure on him. He took Adderall. It is hard to say whether he took Adderall because he was that way, or he became that way because he used Adderall." Therefore, Mimi doubted whether her son's illness was really an illness or rather a reaction to his use of Adderall. At the same time, she was questioning herself about the possibility that her son was using Adderall because he had a mental illness. According to Mimi, her son David started using Adderall in college because he initially thought that he had ADHD. In addition, Mimi and her ex-husband both did not believe that their sons needed therapy even after they were diagnosed with the mental illnesses. When both of their sons were diagnosed with the mental illnesses, they agreed to provide them with medications but did not believe in providing them any therapy. Sally mentioned that both of her brothers also "did not want therapy and just took the meds." Sally, in describing her parent's lack of understanding about mental illness or perhaps denial about the illness in general stated: "my parents did not believe in therapy."

When Sally in the Taylor family first found out that her younger brother David was diagnosed with bipolar disorder she did not want to believe it. She said: "I was surprised; I did not believe it at first. I did not want to believe it because he was doing so well during that time he was in a master's program...he was on a higher level than my other siblings." Sally was surprised and in disbelief. She also questioned the diagnosis initially and felt that maybe her brother had a psychotic breakdown because of using Adderall. However, her brother continued to have problems even after he stopped using Adderall. He is now using medications for bipolar disorder. Thus, at the onset of the illness, the family may have experienced moments of disbelief about the diagnosis. They tried to deny the diagnosis by

looking for other reasons for their relative's behavior. For example, one of the reasons that Sally attributed David's odd and destructive behaviors was the fact that her parents had divorced when David was only 12 years old. She felt that "he had problems because he did not have a male role model." Her mother Mimi also stated that her son David had problems with anger because of his parent's divorce. In describing her son David's relationship with his father Mime said:

He started to show anger in the eight- grade. At that point he really was suffering he never really had a relationship with his father. His problem ...was all because of his father. Even when we separated my ex-husband never came to see him.

If one looks at the statements from Sally and Mimi in the Taylor family when describing the reasons for David's problems, one can see that they were attributing the problem of David's mental illness to the divorce of the parents and in particular to the absence of the father after the divorce. By saying that David's problems are due to the lack of his father's involvement in David's life, the family was shifting the problem to a third party, in this case, the father in order to relieve the pressure of the illness on the family unit. Similarly, by saying that maybe the problem was due to David's use of Adderall, they were shifting the reason for David's behavior to the usage of Adderall thus relieving the emotional pressure of accepting that David had been diagnosed with a mental illness.

In the Lopez family, the caregiver was not in denial of the illness and said that she knew that her husband's behavior implied a mental illness. Emily talked about the many instances where her husband Mico was in denial and thought that nothing was wrong with him. However, after his diagnosis he accepted his diagnosis and according to Emily "his behavior and anger have improved after he started taking his medications."

### **Diagnosis and medical community/triggering event and hospitalization.**

According to Seeman (2009), the family is still not being fully integrated into treatment models for the mentally ill even if families are now seen as “burdened caregivers.” Research on the family caregivers’ relationship with medical providers shows that many times, family members of the mentally ill feel devalued and dismissed from treatment (Jubb & Shanley, 2002).

In this study, most of the caregivers talked about their difficulties regarding the diagnosis of the mental illness and their experiences with the medical community. Their difficulties were the product of several factors including misdiagnosis or delayed diagnosis of the mental illness, a lack of knowledge and/information about the mental illness, and finally, not understanding the long-term effect of the mental illness. In general, the caregivers talked about the difficulties that they had in first trying to understand the mental illness and then finally their experiences after finding out about the diagnosis of mental illness. The road for understanding the mental illness was not an easy one for any of the caregivers. Initially, the caregivers talked about the strange and odd behaviors of their mentally ill relatives. Then most of the caregivers talked about their efforts in trying to understand the illness. The experience of understanding the illness was intermingled with their struggles at times with the medical community. In each case, the correct diagnosis was evident only after an event occurred where the mentally ill relative’s symptoms became worse which clearly pointed out that something was terribly wrong. The apex of the mentally ill relative’s symptoms as a result of untreated mental illness led to the relative’s hospitalization. In each case, that was the point where the medical community finally diagnosed the person as having a mental illness.

The Chemova family experienced much struggle and pain before Violetta was correctly diagnosed. Initially, according to Natasha, the doctors would diagnose her with major depression. In addition, since Violetta's onset started after she had turned 18, the doctors would not talk to her mother without Violetta's permission because at 18 she was legally an adult. According to Natasha, her daughter was "making up many lies and stories that people believed." Thus, the doctors would not believe Natasha when Natasha would tell them that something was wrong with her daughter's thinking. Violetta would talk against her own family to the doctors and consequently, would be diagnosed only with depression. Natasha said: "first they diagnosed her with depression...we took her to the psychiatrist and again they kept saying that it was just depression." Natasha grew more and more concerned about her daughter when she saw that Violetta could not keep a job, acted oddly, and was suffering from delusions and hallucinations. Finally, the triggering event in this family was when Violetta ended up in a catatonic state and was hospitalized. At that point, Violetta was diagnosed with schizophrenia. The police had called Natasha from the hospital because Violetta was unable to talk or move and looked comatose. Natasha described her experience of the time her daughter was hospitalized with schizophrenia as follows:

One day she looked like she was in a coma. I was afraid of losing my daughter. She was asleep and not waking up, not responding to any kind of stimuli. She was alive but not talking, not moving, unconscious. I was scared...finally they diagnosed her with schizophrenia. This was about 6 years ago. That was when I realized that my daughter had a mental illness.

Natasha finally understood that her daughter had a mental illness after she was hospitalized in a catatonic state. Before that, Natasha did not understand what her daughter

was experiencing and believed the misdiagnosis of the professionals who thought that she was suffering from depression. She was correctly diagnosed and was given the proper medications only after this incident.

Natasha recalls that Violetta ended up in jail during the onset of her illness. She was having a psychotic breakdown and was upset and screaming. Her roommate called the police. When Violetta saw the police, she attacked them with a knife. “Instead of taking her to a hospital, they took her to jail.” Natasha hired a lawyer who was able to get her out of jail because when she attacked the police she was delusional. Getting Violetta out of jail took at least a year. According to Natasha, that time was one of the “most difficult times” in her life. While in jail, Violetta saw a psychiatrist who was able to give her the proper medications.

Sally, in the Taylor family, talked about the time when her older brother Mike was diagnosed with schizophrenia. He was in the hospital for over a week and was medicated as soon as a diagnosis was made by the doctors. Before that event, Mike was misdiagnosed as having ADHD. The triggering event in this case was when Mike was hospitalized because he overdosed on drugs and was unconscious for several days. Sally described that experience as follows: “He ate some mushrooms...he was hospitalized and was out for days. They finally diagnosed him with schizophrenia.” Sally also said that in addition, about ten years ago, her brother Mike was caught selling drugs and ended up in jail where he finally received the right treatment (medications and therapy) for his mental illness.

Sally’s younger brother David had the onset of the illness while he was finishing his Master’s degree. David had suffered a few psychotic episodes while he was living on campus in another state. The police called the family because David had a psychotic breakdown. While describing the triggering event, Sally said: “He was found running around

naked on a one way street...the police arrested him and took him to a hospital. That was when he was diagnosed with bipolar disorder”. Sally also talked about other psychotic episodes that her brother David experienced during that time period. In another incident, David destroyed someone’s windshield with a hammer. Then, the most recent one that Sally recalled was when David threw furniture out of his bedroom window and the neighbor called the police. After experiencing the psychotic episodes, David was no longer able to focus on his studies and was unable to complete his last month in his Master’s program. He moved back with his family and discontinued his education.

In the Duran family, Caroline’s father James was diagnosed with a mental illness when he was hospitalized at the age of 70. Before that, there had not been a clear diagnosis. One of the reasons may have been Caroline’s parents getting a divorce right after he started to show symptoms of his mental illness. Caroline said that her father started living on his own after the divorce. Caroline stated that when her father was 70, his health started to deteriorate. She said:

He was having seizures and was unable to move. He ended up being hospitalized...his brother placed him in a nursing home. When they placed my father in a nursing home on the east coast, I thought that if he was going to be in a nursing home then he should be close to me so that I can take care of him.

Caroline’s uncle helped to move her father to a nursing home close to her. The doctors concluded that James had Parkinson’s disease. While the doctors ran some tests on James they discovered that James had frontal lobe damage. Caroline said:

The doctors did an MRI on my father and found that he had frontal lobe damage and they said that it must have been there since he was twenty. When the doctors talked

to my aunts and uncles about the frontal lobe damage, they were told that my father had been diagnosed with schizophrenia or bipolar disorder in his teens when his acting out behaviors had escalated...in his teens, doctors had diagnosed him with either schizophrenia or bipolar disorder or both. He was never medicated.

Finding this out from her father's family members was not a surprise for Caroline who always suspected that her father had a mental illness. Finally, the doctors at the nursing home diagnosed James with schizophrenia. In addition to being treated for Parkinson's, James was treated with anti-psychotic medicine to control the symptoms of schizophrenia. According to Caroline, his behavior changed when he was medicated. While describing the effect of the anti-psychotic medications on her father Caroline stated:

When he had all the anti-psychotic medicine, he became mellow. Then, one doctor took him off the drugs and he became violent and aggressive. He went back on the medication and he was gentle again. For the last ten years of his life my father was mellow.

In this case the triggering event leading to the diagnosis did not occur until Caroline's father was hospitalized with Parkinson's disease. This allowed the doctors to evaluate him for a mental illness and medicate him for schizophrenia. According to Caroline during the last 10 years of his life, James did not have delusions and she was able to have a "normal relationship with him."

For the Lopez family, the diagnosis of mental illness came after many years of misdiagnosis. Emily talked about how her husband Mico had always been violent and lost control of his emotions when he got angry. She talked about her frustration with the medical community. She said:

At first they did not understand that Mico had a mental illness and would not medicate him. He was diagnosed by a clinic once but they did not give him anything...the doctors did not understand the suffering at the beginning...once I am there they say now we can see the whole picture...they did not medicate him until he was hospitalized and they were going to let him out and I said no... how couldn't they see it. Yes, the doctors did not understand.

Thus, Emily talked about the frustration that she experienced when she was trying to explain to the doctors that her husband had a mental illness. She said that they did not get a full picture until they met her. She was also frustrated when they would just send Mico home and would not medicate him for his illness after each angry episode where he would lose control and become verbally abusive to his family. This family experienced a triggering event which caused Mico to end up in a hospital where he was finally diagnosed with a mental illness. Emily said that her husband in a moment of rage and anger had threatened to “kill the whole family and bury them in the backyard.” She told him that he had to go to the hospital to be treated. If he did not go, she was going to call the police. Her husband Mico agreed to drive himself to the mental ward in the hospital and told them what he had said to his family. CYFD got involved and he was diagnosed with bipolar disorder. According to his wife Emily, she felt “relieved by the diagnosis” perhaps because this meant that there was a reason for Mico’s behavior and that something could finally be done about his mental illness.

Emily also recalled that when Mico was a teenager, he had been arrested for theft. At that time, Emily was his girlfriend and did not know that Mico was involved in robberies. When she found out she broke off the relationship. While Mico was in jail, he kept writing

to Emily and told her that he wanted to change. Emily and Mico got together again and got married when Mico was in his early twenties.

In summary, the family members experienced great psychological stress and burden during the time of the onset of the illness. The relatives were correctly diagnosed only when the mentally ill relatives were either hospitalized or sometimes ended up incarcerated because of the behaviors triggered by the mental illness. Thus, the suffering that the family members experienced at this time was heightened because of the uncertainty of not knowing why the mentally ill relative was acting in a certain manner.

**Finding the right medications.** During the onset of the illness and then when the families learned that their relative had a mental illness, the most important aspect both for the families involved and for the mentally ill relative became finding the right medications. When a person starts taking anti-psychotic medications, effect is not immediate. It may take several weeks before the effect is noticeable. Antipsychotic medications are required to treat people who have been diagnosed with schizophrenia. These medications control the brain by controlling the neurotransmitters dopamine and serotonin. In general, these drugs have the potential of creating side effects that are neurological in nature. One such side effect is tardive dyskinesia which is a movement disorder. Usually the psychiatrists prescribe the lowest amount necessary to control the symptoms. They try out different medications in different dosage to accomplish the desired results (Mayo clinic, n.d.).

Consequently, in dealing with the process of getting the right medications for the mentally ill relative, the family caregivers saw their loved one go through many physical as well as mental changes with the hope that the right combination of drugs would help control the symptoms. Each caregiver talked about how the medications affected the mentally ill

relative and how difficult that process was. This was especially evident with the Chemova family and the Duran family. For example Natasha in the Chemova family talked about how difficult it was to see her daughter becoming stiff after she first started to take her anti-psychotic medications. In describing her daughter's difficulties with the Tardive Dyskinesia after she started her medications Natasha said:

She lived with me. I took care of her. Because of the side effects of the medicine she was unable to do a lot of things for herself because she was very stiff. The doctors told me that it will take time for her to adjust to the medicine. I fed her; I bathed her, and did everything else.

Natasha took care of her daughter when she was first medicated because she was not able to take care of herself as a result of the side effects of the medications. It took a long time for the doctors to find the right dose and the right combination of the drugs. There were times when Violetta was "out of it" according to Natasha and looked like a "zombie." Nowadays, Natasha states that her daughter is taking the right combination of drugs and is able to take care of herself.

In the Taylor family, Sally talked about her brother Mike's experience when he started taking the antipsychotic medications. She described her sadness over how her brother changed when he started to take his medications. She said:

After the diagnosis, he was like a baby, it was sad, his body was there but his mind was gone...the worse years was when he was on medications...he could not play the guitar anymore. I felt frustration, sadness that he was gone.

Sally felt sad and frustrated and felt like her brother was "gone." When describing the effect of the medicine on her younger brother David, Sally said: "that was not the brother

that I knew. He was not the same.” When describing her younger brother David on the anti-psychotic medications she said: “He was like a zombie. He did not do anything else, just go to the bathroom.” Sally also stated while living with her David decided to cut his pills in half without consulting the doctor. Sally became concerned and felt that she was not able to control him. David finally moved in with their mother Mimi.

In the Lopez family, Emily also talked about the time when the doctors were trying to find the right medications for her husband. In Emily’s case, her husband’s main problem which is anger, needed to be controlled, for he got violent and verbally and emotionally abusive to his family. Emily kept asking the doctors to medicate her husband for his anger. Finally, when Emily’s husband Mico was diagnosed with bipolar disorder, he was placed on medications to stabilize his moods. While describing her experience during the time that Mico was starting to take the drugs prescribed by his psychiatrist she said:

The doctors told me that it will take time for him to adjust to the medicine. The medication made him like a zombie and in order to keep family balance he could not be all drugged up. He went through a lot of medications. Seroquel would make him a zombie.

In the Duran family, Caroline mentioned that her father changed when he was finally medicated at the age of 70. In Caroline’s father’s case, the medication changed him from an angry person to one who was kind and mellow. Caroline described her father as being so gentle and kind after he was medicated. She said: “finally, he was on medications the last few years of his life; he was stable and kind and peaceful.” In this case, the medications enabled Caroline to see a different side of her father, a side that she saw only after he was medicated.

In summary, the caregivers, the mentally ill relatives, and the psychiatrists had to work closely together to get the right combination and dosage of the medications. Once medicated, the mentally ill relatives showed reduction of the psychotic symptoms but at the same time the medications had some strong side effects. Life during the onset of the illness was a time in the families' lives when the families struggled through much stress and anxiety until they came to the realization that their relative indeed had a mental illness and that their lives were going to change forever.

**Loss of balance.** The onset of the mental illness in the families' lives was also the time when the families lost their homeostasis or balance of the family. Each family member had to change his or her behavior in order to maintain the balance. The caregivers were the ones to ensure that balance was maintained in the family and much of the pressure of taking care of the mentally ill relative fell upon them. Each time Violetta got upset or was admitted to the hospital because of her mental illness, her mother ensured that the family was not disturbed. She did all of her daughter's chores, paid all her bills, and took care of all unfinished business. She was also the one who took care of her daughter whenever she was in the hospital. Natasha had taken on many of the pressures in order to maintain balance in the family's life. As a result, she felt stressed most of the time. She said: "I am ready to snap, and I get angry easily...I am always taking care of my daughter."

In the Taylor family, Sally usually helped her brothers out whenever there was a problem. When her older brother Mike was hospitalized because of a drug overdose and because he had a psychotic episode, Sally left her studies "to take care of her family." She also became the one who had difficulties with her own life and initially was not doing well in college. Sally attributed her issues at that time to "the pressures at home." She also started

to drink and use a substance during her first year in college. When her younger brother was hospitalized and was diagnosed with bipolar disorder, his mother Mimi became his caregiver. She mentioned being “stressed and worried”. Mimi talked about being constantly worried about her son David’s future. Currently, David lives at home with Mimi and does not have a job. According to Mimi, she is trying to help him to get back on his feet. She is trying to get health insurance for him so that he can get proper psychiatric treatment. Her son is depressed and is not taking any medications. Mimi feels that she will “convince” her son to start taking his medications and to see a psychiatrist. She “takes care” of him on a daily basis. However, according to her daughter Sally, Mimi has “not been taking care of herself”. Sally feels that her mother should take care of her own health. Sally is worried about her mother’s health and feels upset about the fact that her mother will not be able to retire next year when she turns 65 because she has to help David. In this case, Mimi takes on all the stress from her son and tries to balance the family unit by providing for her son’s needs. She takes him to the doctor, pays his bills, and ensures that he is functioning. Mimi feels that her goal is to help him to get help and to “be happy.” In this family, Sally and Mimi both try to balance the family system by taking on many of the responsibilities for the two mentally ill relatives.

In the Duran family initially Caroline’s mother was the caregiver for her father. When Caroline grew up she became the main caregiver for her father. Caroline’s mother used to be stressed and worried about her children when her father got angry and violent with the family. Caroline stated that her mother used to “protect her children” when her father was having a psychotic episode. She would send Caroline to a friend’s home and would tell her two children not to “talk to daddy today.” She was always concerned about her children’s safety. Then, when Caroline became older and her mother passed away, she

became the one who was always worried about her father. She started experiencing anxiety and depression. She mentioned that she and her sister both “had tons of therapy for years”. Her sister also suffered from depression and was an alcoholic for many years before getting treated and eventually healing from her addiction in her late thirties. Caroline stated that her family suffered much distress when they were living with their father. When their life with their father became “unbearable” her mother divorced her father. Caroline said: “living with my father became unbearable...it was a nightmare.” However even after the divorce, her father continued to come to the house and continued to pursue her mother. Caroline recalls her father “forcing himself on mother and trying to kiss her”. This created a stressful environment for the family. Caroline recalls that when her mother remarried, her step-father had to hit her father with a vase in order to get him away from the mother. The police got involved and according to Caroline, her step-father “went to jail and needed stitches on his head.” Looking back at her experiences, Caroline feels that her depression and her sister’s depression were an outcome of their past.

In the Lopez family, Emily is burdened and stressed each time her husband Mico becomes violent and emotionally abusive to his family. She stated that she was becoming more and more stressed especially when she found out that she was ill and had a tumor. She has had 10 surgeries to remove the tumor and suffers great pain on a daily basis. Emily stated “I get more stressed because of Mico especially now that I am ill.” She is the one who has to ensure that her children are safe each time her husband becomes abusive. She has left Mico several times because of his anger. When Mico becomes angry and abusive at home, Emily takes her children and goes to her mother’s home. She is also the one who calls the police or the ambulance when things get out of hand. She ensures balance by keeping her

husband away from her children each time he is abusive and she is “always protecting them.” Emily also ensures her family’s financial stability by working and by asking for help from her own extended family. Thus, in order to ensure family stability, Emily gets help from her extended family such as her own mother, her brothers and sisters, and her cousins. Emily talked about how her cousins “always included Mico in everything.” Even if Mico does not have any friends anymore, Emily’s extended family includes him in all the activities. Emily makes sure that her husband Mico gets therapy and that he participates in family therapy. Hence the extended family such as the children’s maternal grandmother, Emily’s cousins and aunts and uncle help to keep balance in the family unit. According to Emily, her mother was always “against her marriage” and felt that Mico “was a lot of trouble.” Each time Emily is hospitalized because of her health problems, her mother takes care of her children. Each time Mico becomes abusive to the family and leaves home, her mother helps out with taking care of the children and paying the bills.

**Family’s relationship: (1) emotional health/psychological distress, and (2) odd or destructive behaviors.** Mental illness of a family member affects the relationships all the family members have had with each other. Once mental illness is introduced the family unit changes. In telling their stories, the caregivers talked much about how the family members reacted to each other as a result of the mentally ill family member’s behavior. The majority of the issues that all the caregivers in the four families talked about were related to the family’s relationships with each other. Most of the time the mentally ill family member’s behavior caused family members to react in many different ways. Family members experienced much distress because of the mentally ill relative’s behaviors. This was especially relevant at the onset of the illness when the family did not understand why the

mentally ill relative was reacting in a certain way and this caused the caregivers much confusion, pain, and many times shame because of the stigma attached to mental illness.

*Emotional health/psychological distress.* Natasha in the Chemova family was frustrated at the fact that her daughter keeps making the same mistakes over and over again. Yet, Natasha ensures that her daughter keeps living her life and keeps getting what she needs. When asked what her daughter does that is frustrating she stated:

She makes friends with the wrong people, gets into trouble and gets used by them.

She says that she will change but she does not change...she makes the same mistakes over and over again. This has been going on for 6 years.

Sally in the Taylor family recounts her experience of helping her brother over and over again and seeing no results. When her brother David was diagnosed with bipolar disorder, she tried to help him get the right treatment. She took him to several psychiatrists, and tried to get him to apply for disability. She remembers taking him to several places and finally found that her brother did not want to get therapy. In addition much to her distress, she saw that her brother had started to take only half of his medication. This was “frustrating” she stated. “I have a family of my own, and there is only so much that you can do.” She went through a similar experience with her older brother Mike. She tried to help him and wanted him to get therapy. Her older brother was not working. She stated that he was “just lying on the couch all day.” Finally, after trying to live with him to take care of him, Sally had to move out. One day he became violent with her boyfriend because Sally and her boyfriend did not want to give him alcohol because he was taking medications. Sally was very upset and felt that she could no longer live with her brother Mike.

In the Chemova family, Natasha recalls her experience at the onset of her daughter's illness as a difficult time. At the onset of her illness, Natasha's daughter was delusional and believed that her family was hurting her. Natasha recalls that her daughter started to act oddly when she was around 17 which was the onset of her illness. When describing the onset of the illness and the behaviors that her daughter displayed, Natasha said: "my daughter started to say that she saw visions in her room at night. She would even talk about seeing monsters and things like that...and then it started to get worse." Natasha stated that about 7 years ago she was traveling with Violetta on a plane. The family was flying back on a plane on a 10 hour overnight trip. In the middle of the night when most of the passengers were sleeping, Violetta stood up in front of the plane and started to read her poems to the passengers. In describing Natasha's odd and destructive behavior Natasha also added that Violetta made friends "with the wrong people." Natasha was concerned about her daughter's friends because she felt that her friends were taking advantage of Violetta and her disability money. While describing her concerns about her daughter's choice of friends, Natasha stated:

Violetta cannot discriminate. If your life is in danger because of the people and maybe these people might rob you or harm you, you don't want them in your home. We cannot trust these people." She calls people "friends", people that she just meets...she is desperate for friendships but many people do not understand her and do not want to hang out with her. She gets hurt over and over again. The only people that remain her friends are the people who are abusers and advantage takers or people who are not all there."

Natasha feels that at the onset of her illness, her daughter Violetta hurt the family because of her illness. According to Natasha one of the most difficult times in her family was when Violetta accused her own family in court by stating that her family tied her up and beat her. This was the product of Violetta's delusions. Natasha stated:

She accused us her family falsely in court and said that we beat her. She was all bruised up from a fight she had with someone and went to the cops and told them that we had locked her up and beat her up. We were very hurt and did not understand why she did that. Finally, the case was dropped...but the emotional harm that we went through because of this experience was never healed. Even if Violetta apologized and eventually came back to us, we feel like we cannot trust her. She can turn on anyone even her own family. We know that she is ill and yet it still hurts a lot.

Hence, even when the family understood that Violetta's actions were governed by her mental illness, the family members were still very hurt. Natasha also talked about the psychological distress that her daughter's behavior caused in her and the family in general. On one occasion while describing her own emotional health which she believes was caused by her daughter's illness and behaviors she stated: "I am on the brink of a nervous breakdown. "I am exhausted. I snap at people." Around 6 months after her daughter Violetta was diagnosed with schizophrenia, Natasha had a major car accident and was hospitalized for several months. She feels that she had the car accident because she was thinking about her daughter and was worried about her. It has been three years since she had the accident, and she still needs physical rehabilitation for her neck and head area because she was severely hurt when her car was totaled on a major highway. After being hospitalized

for two months, she was not able to return to her job for almost two years. She remembers that the day of the accident she had been feeling very depressed and sad because she was thinking about her daughter's future. The night before the accident the family had gone out to celebrate Natasha's birthday. Natasha said that her daughter was "not doing well because of the medication that she was taking". While everyone was celebrating, Natasha was feeling that her daughter would never be the same again and she remembers feeling like she did not care about herself anymore and that she was exhausted from all the problems she had faced trying to care for her daughter. She recalls that the day of the accident she was on her way to work and was driving on the highway to another city. She clearly remembers being very worried about Violetta. Looking back, she realized that maybe she was driving fast or not paying attention when her car hit the side of the road and went off the road. The car turned on its side and Natasha hurt her head against the windshield. She became unconscious and regained consciousness when the paramedics and the police arrived. The accident was a pivotal point in Natasha's life for that was the time she decided that if she was going to have to take care of her daughter forever, then she also needed to take care of herself.

At another point, while describing the effect that her daughter's illness had on her emotions she said: "even one day with her drains me. My job gets impacted because of my daughter." Thus, Natasha clearly felt that the impact of her daughter's illness infiltrated many areas of her life from her emotional health to her job.

Sally in the Taylor family, also felt Mike's mental illness caused much psychological distress within her family. That was the time when her brother was a teenager and had started to behave in an aggressive manner at home. He became rebellious with the family and started to use and sell drugs when he was in high school. Her parents first took him to

get help and tried to stop him from using and selling the drugs. In describing her “lived experiences” with her family, Sally recalled many instances of feeling scared of her brother’s anger and tantrums and being distressed about her brother’s growing arguments with her father. While describing her brother’s behavior at the onset of his illness she said: “he would get angry and he would destroy stuff and yell and scream.” When describing her feelings about the arguments between her father and her brother she stated: “it was scary.” She talked about the change in the family’s relationships that occurred at the onset of the illness. She said: “A lot of issues started coming up. My parents could not handle him and his acting out caused issues in the marriage. There was a lot of yelling and fighting between mom and dad.” Thus, according to Sally, the conflict between her parents and her brother Mike started to cause issues in her parent’s marriage. In addition, Sally also felt that her brother’s behavior was affecting her negatively. He forcefully made her participate in illegal activities when she was around twelve or thirteen years old. She said:

My brother made me sell drugs from our home ...there was violence and there was physical fighting. My father broke my brother’s arm in a fight...I don’t do well with violence now. My brother was a time bomb waiting to go off.

Sally added that according to her mother, her brother caused the divorce of her parents. Sally stated that her mother said: “your brother Mike was the root of all our problems.” In addition, according to Sally, her father became dysfunctional as a result of his financial problems coupled with the problems that the family was facing as a result of her brother’s mental illness. Sally stated that when the fights at home between her parents as well as the arguments between her father and her brother got worse, her father tried to commit suicide. When talking about her father’s suicide attempts she stated: “he felt that he

could not provide for the family anymore.” This was also the time when her father’s company “started to go under.” Sally felt that these were the reasons for her father’s decision to leave the family and get a divorce.

***Odd or destructive behaviors.*** In the Duran family, Caroline talked about how her father’s odd and destructive behavior had affected her family life. Her father had many difficulties living with his wife and his two daughters. Caroline talked about her life with her father as a nightmare. She stated: “It was a nightmare, it was horrible growing up.” Caroline stated that when the father was living in the home, he was violent and was always starting a fight. In describing her father’s odd and destructive behavior Caroline stated:

My father was very erratic. There were times when he was sweet, but he could swing so fast and became highly angry and enraged and started dishing out punishment. Like over something very small he had said that you cannot be at the Christmas pageant at school. What I have been told is when I was a baby to get back at my mother, he picked me up from my crib and then he dropped me and then he threw me down the stairs.

This event told to her by her mother seems to be a major event in the family’s life. Her mother then brought a priest to the home and made the father promise never to touch Caroline again. Caroline’s parents eventually got a divorce. While describing her father’s behaviors and his life after the divorce Caroline said:

He went to various places like boarding places and then a YMCA and pretty much homeless shelters. He could not keep a job, he couldn’t manage structured living such as doing laundry getting somewhere on time. He had no bank account, no driver’s license, and no credit cards.

Caroline also talked about how her father harassed her mother after she gave him a divorce. She said: “he would come to the house and hug her and kiss her and she would try to push him off. I would call the police.” After Caroline became an adult and started her own family, she kept track of her father’s whereabouts. Once a social worker called her and told her that her father who was living in an apartment for people with low income was acting oddly and that she needed to check in on him. Caroline went to see her father. When describing her father’s apartment she stated:

I went to his apartment. There were empty cans of food... this is when he was sixty five and he was qualified for low income housing, he was taking people from the street. The kitchen was filthy. There was no furniture, a couple of towels or such rags. He was peeing in the corner of his living room to avoid the person across the wall.

According to Caroline, her father had a delusion that there was a man looking at him from the other room while he was urinating in the bathroom. For that reason, her father used to urinate in the living room when he was living in low-income housing.

Mimi in the Taylor family also recalled the time when her son David started to act oddly which was at the time of the onset of his illness. She mentioned that when he was finishing his Master’s degree and only had a month left to graduate, he had a psychotic breakdown. The hospital where he was admitted called the family to tell them that he had been hospitalized and was diagnosed with bipolar disorder. They also told her that it was bipolar disorder with psychotic features. While describing a psychotic incident that her son had experienced she said:

He ruined someone's bike. He took the hammer and got the windshield. He threw furniture out of his apartment. The girl that lived upstairs was worried and upset. The girl finally called the police...it was too much pressure on him.

In the Lopez family, Mico has caused much anguish and emotional pain to his family. His wife Emily talked about how her husband's odd and destructive behavior has affected her daily life. Her husband was diagnosed with bipolar disorder only about three years ago. While talking about her husband's destructive behavior Emily stated: "Mico always had a very bad temper and he becomes angry and violent when he is not medicated." Emily also talked about Mico's disruptive behavior at work. She said: "he lost all his jobs because of his temper. He has problems with authority." In describing Mico's behavior when he gets angry at Emily stated:

Those eyes get dark and evil and his mood gets up there. It is a struggle for him I can see the struggle in his eyes when he is that way. The bad person is pretty evil. I want nothing to do with him. I make him get out and we leave...he breaks things throws things. If it is a simple thing like putting the kids on time out, he will try to drag him and take him out.

When Mico gets angry his children are afraid of him and he has to leave the home in order to calm down. When Mico becomes violent, Emily tries to protect her children from him and tells him to leave the house. By removing Mico from the family during the time that Mico is having an angry episode Emily ensures that the children are safe and that they do not get hurt. When Mico is displaying his anger and is getting angry with his family, he becomes verbally abusive with his wife. When Mico is blaming his wife and his children for his anger

and frustration, he is releasing his inner stress from his illness. Emily confirmed that when he is medicated, he is more in control of his emotions.

An odd behavior that the family caregiver in three of the four families talked about when referring to the odd behaviors of their mentally ill relative was that the mentally ill relative seemed to be two persons at the same time. Sometimes the mentally ill relative seemed happy and showed positive qualities. At other times the relative was angry, or enraged, or behaved in an irrational or destructive manner. Hence many times the behavior of the mentally ill relative was unpredictable.

For example, in the Taylor family, Sally described Mike's behavior as: "when he was not delusional, he was friendly and was extremely outgoing and loved his family and friends." When her brother Mike was upset or angry Sally described his behavior as "scary." When Mike was angry, he was violent and Sally was afraid of him while growing up. Thus, the same person could be very outgoing and friendly but could become "scary" when he became angry.

Caroline in the Duran family talked about her father's two sides and said:

Father was two people. When he was good he was like St Francis, loved animals and cared about the poor, or he was a crazy agitated person. There were times when he was sweet but he could swing so fast and became highly angry and enraged.

Caroline described living with her father's behavior as having been "very hard" for her and her family.

Emily in the Lopez family also described her husband as being two different people at times. When describing her husband's behavior she said:

He is either super-good or he is super bad...when he is in a normal state of mind he is awesome. When he is good he is part of the family. When he is in a normal state of mind he is awesome. He takes care of the kids. He will give me massages. He will play with the kids. When he is good he is part of the family, we can enjoy each other as a family and as mama and daddy.

Thus, when the mentally ill relative is not displaying symptoms of the illness, or is medicated, his or her behaviors are pleasing to the family members. When the mentally ill relative is displaying disturbing or destructive behaviors the behaviors are unpleasant and cause distress and disturbance in the family members.

In summary, when describing their experiences about the time when the mentally ill relative was diagnosed with the mental illness, the family caregivers talked about several factors that led to the diagnosis of the mental illness. In the beginning stages of the mental illness, the family noticed the symptomatic behaviors of their mentally ill relative. This was usually when the relatives were between 15 and 20. The families started seeing that “something was wrong” but did not understand what it was. Most of the family caregivers went through a period of confusion because they were not knowledgeable about the symptoms of mental illness. The family caregivers talked about the psychological distress that they experienced as a result of the struggles that they faced with the medical community. They felt that the mental health and the medical providers did not understand their concerns and that initially the mentally ill relative was misdiagnosed. In each case, the correct diagnosis was evident only after an event occurred where the mentally ill’s symptoms became worse. The apex of the mentally ill relative’s symptoms as a result of untreated

mental illness led to the relative's hospitalization. In each case, the hospitalization was the point where the medical community recognized that the person had a mental illness.

When describing the steps that led to the diagnosis of the mental illness, most of the caregivers talked about their efforts in trying to understand the illness. Many times, after finding out the diagnosis, there was a time of disbelief. Some caregivers did not believe that their relative had a mental illness and in some cases, were in denial. Once they accepted the mental illness, family caregivers needed to understand treatment and the effect of the anti-psychotic medications. Family caregivers talked about the difficulties of "finding the right medications."

Finally, this is the stage where family caregivers started to experience a change in their own emotional health as a result of tasks associated with the caregiving of their mentally ill relative.

### **Synopsis of Family Systems Theory during "life during the onset and diagnosis of the mental illness"**

In looking at the application of family systems in the analysis at this stage of the mental illness, one can understand that family caregivers experience change in many areas of their lives. The emotional unit of the family was unbalanced as a result of the mentally ill relatives' symptomatic behaviors. The family started to experience confusion and pain due to their experience of seeing their mentally ill relative change or "act in a strange manner." Family caregivers tried to maintain homeostasis within the family by taking on many of the stress and burdens associated with the mental illness. Thus, in trying to maintain balance and unity, family caregivers at times looked for different mechanisms. Sometimes they changed their behaviors to accommodate the mentally ill relative's odd behaviors. During the onset of

the illness, the families started to deal with the medical community, understand the mental illness, and the side effects of the medications. This caused further emotional stress and burden for the families. Some family members talked about their emotional health being impacted which caused imbalance in their own emotional health. In each family, the family caregiver experienced psychological distress and burden because of taking on many of the responsibilities of the mentally ill relative. The caregiver bearing all the stress was the identified patient. This implies that as the identified patient, the family caregiver was emotionally affected by the mentally ill relative's behavior and developed emotional problems. For example, in the Taylor family, Sally took care of her brothers each time they needed her help. She gave up her semester in college to help Mike and took care of David in trying to get him the right treatment. She was also the one who was affected by the stress created in the household as a result of the problems with Mike. She started experiencing symptoms of the stress and pressure and started using a substance while in college. In the Chemova family, Natasha was the identified patient for she took on all the pressures of her daughter's behaviors. As a result, she suffered from heightened stress and anxiety. In addition, she "did everything" to help her daughter including taking on the financial responsibilities, and making sure that she was not making friends with people who took "advantage of her." In the Duran family Caroline and her sister both were the "identified patients" for they took on many of the stress and burdens from the problems at home. They were both depressed in their early twenties and needed much therapy to heal their emotional pain. Caroline was also always worried about her father which caused her emotional distress.

Another prominent change that came about from the mental illness was the effect of the illness on the relationships of the family members with each other. The behavior of each

family member affected the other family member's behavior. According to Bowen's theory (1994) this is circular causality where the behaviors of the family members affect each other in a circular manner. During this time, the conflicts in the family created emotional triangles where one person displaced their pressures on to a third party or reason in order to relieve the pressure of the lack of balance in the family unit. For example, Mimi and Sally in the Taylor family triangulated David's symptomatic behaviors to the absence of David's father in his life. Mimi also triangulated David's mental illness to the use of Adderall. In addition, during the time of the onset of the mental illness, the help of the medical community became crucial for family caregivers. The family unit was no longer secure and whole with the mental illness and family caregivers started feeling a need for more support from the medical and mental health providers in order to be able to adjust to the changes that had been created by the mental illness in the family unit.

### **Life after the Onset and Diagnosis of the Mental Illness**

During this stage, some of the issues that caregivers started to experience at the onset of the illness continued to be present after the onset of the illness. For example, the families' relationships with each other which included the effect of the mental illness on their emotional health, continued to be affected.

For the time after the onset and diagnosis of the mental illness the following sub-themes emerged: (1) Relationship with society and community/embarrassment and stigma; (2) Burden associated with lack of financial support; (3) Coping mechanisms/strategies/gaining strength; and (4) Worry about the mentally ill relative's future.

After the onset of the mental illness, family caregivers realized that their family life had changed significantly. The caregivers talked about the many challenges that came about as a result of the mental illness. They talked about their worries and concerns such as their relationship with society and the community including the embarrassment they felt as a result of their mentally relative's behavior and the stigma that they experienced. Family caregivers also felt burdened by the lack of financial support. One of the major burdens that family caregivers of the mentally ill face is financial stress (Dyck, Short, & Vitaliano, 1999). Financial stress can result because some patients are not self-supporting and lack financial resources (Potaszniak & Nelson, 1984). The time after the diagnosis of the mental illness was marked by this burden because in most cases, the mentally ill relatives were no longer able to hold on to a job on a permanent basis.

Another area that the family caregivers talked about when referring to the time after the onset of the illness was their worries related to their mentally ill relative's future. Rose et al. (2006) discovered that one of the greatest burdens experienced by the caregivers was their worry about their mentally ill relatives' future. The family caregivers talked about their worry that their mentally ill relative was not able to support himself or herself financially and lacked life skills. They worried about who would take care of their relatives when they were gone. Family caregivers developed many strategies to be able to cope with the continuous odd and sometimes destructive behaviors of their mentally ill relatives. They also developed many methods of self-care and gaining strength.

**Relationship with society and community/embarrassment and stigma.** According to research by Corrigan, Watson, and Miller (2006), often the stigma experienced by family members leads to feelings of shame, contamination, or guilt. The family caregivers

described many experiences where they felt ashamed and embarrassed because of their mentally ill relative's behaviors in public places or in front of strangers. One of the reasons may have been that they felt that society would judge their mentally ill relatives because of the stigma that is attached to individuals with mental illness. In the Chemova family, Natasha talked about how her friends did not understand her daughter's illness and had stopped inviting her to many social gatherings after her daughter became mentally ill. For the past 6 years she has lost many of her friends because she felt that they did not accept her daughter or felt uncomfortable around her. For this reason, Natasha preferred not to see her friends. She also talked about how her daughter embarrassed her by asking strange questions in public or by acting in a strange way. In explaining her feelings of embarrassment in front of other people, Natasha said:

When I am with my daughter, I cannot meet anybody because if I meet anyone then she embarrasses me in front of them...I feel ashamed and embarrassed when my daughter says something out of context to my friends.

Sally in the Taylor family, also talked about her embarrassment in front of her college friends when her brother was "all drugged up from the meds and would act strangely." Sally added that her mother Mimi would get embarrassed at the way her son David acted in public. Sally said: "I think that my mom felt like a failure and was embarrassed as well. There was always stigma. My mother felt that people blamed her but she also does not want to believe that."

Caroline in the Duran family talked about many instances when her father's behavior would make her feel shame and embarrassment. She talked about the time when her father "walked around town with a suitcase in his hand." She also talked about the love letters that

her father used to write to her mother after they were divorced. He would write things outside of the envelope such as how much he loved her and she was embarrassed because “everyone could read what he wrote.” Caroline recalled an incident where her family had gone to church when she was probably seven or eight years old. Her father stood up in church and argued with the priest. Sally said: “he got up in front of church and told the priest that there was too much emphasis on hell.” Since her father was doing this in front of everyone attending church, Caroline remembers feeling very embarrassed by her father’s behavior. Another embarrassing incident for Caroline was when her father had forcefully kissed her girlfriend on the lips. While talking about this particular incident, Caroline said: “the illness was embarrassing.”

Emily in the Lopez family talked about her shame and embarrassment with her husband’s behavior in public. She said:

I hate going to stores with him....he says don’t touch that to the kids and I say stop people are looking at you it makes me embarrassed. Just like that in the stores a kid says something and he starts. In a restaurant....like if our kid does not sit down or plays with the napkin he goes off the rocker. I tell him eat your food and do not pay any attention to the kid...once the neighbors called the police because Mico was screaming at us, lost control and was enraged. They do not understand it is mental illness. The neighbors stopped talking to us because of Mico’s behavior.

Emily was embarrassed because of this incident and at the same time saddened because the neighbors did not understand that Mico had a mental illness. In addition, she felt stigmatized because the neighbors no longer talked to her or her children.

In order to deal with the embarrassing moments, the family caregivers avoided situations where there was a potential for the mentally ill relative to make them feel embarrassed in public places. Consequently, they eliminated the behaviors that could trigger the unwanted behaviors from the mentally ill relative. In many cases, such as in the case of Natasha and Emily, they chose to sacrifice their own personal leisure time to avoid the lack of harmony that occurred when they placed themselves where their mentally ill relative would act in a certain way. For example, Natasha gave up meeting with her friends and did not socialize much after her daughter started to behave differently because of her mental illness. Emily, stopped going out with the whole family in order to avoid the embarrassment she usually experienced when Mico lost control of his emotions in public places.

**Burden associated with lack of financial support.** The caregivers in all four families were affected financially. In general, family finances were a major cause of distress. The caregivers talked about the fact that their mentally ill relative was usually unable to hold a job or to keep a job. Some of the reasons for not being able to keep a job were the mentally ill persons' inability to be persistent, their lack of social skills, and their lack of life skills. Their lack of life skills sometimes included overspending, poor hygiene, and poor social skills.

For example, in the Chemova family, Natasha said: "if I had a normal daughter, I would not have to keep supporting her at the age of 30." She also stated:

I am always paying for something for her because she runs out of her disability money quickly. It is a big burden on me. I give her whatever she needs. Violetta cannot keep a job. She always acts strangely at the job and gets fired. She does not realize how she should behave in certain situations.

According to Natasha, one of the reasons for Violetta getting fired from her job was because she lacked social skills and did not know how to behave in certain social situations. For example, when Violetta was 18 years old, she worked at a McDonald's and had to work at the cash register. She ended up buying food every day for some homeless people. They would come to the McDonalds every day and she would pay for them until the manager told her that she could not do that because the place was getting filled up with people who were dirty and smelled badly. She insisted on doing it every day until she was fired. Natasha talked about how her daughter "did not understand what people expected from her." Natasha also said that her daughter lacked life skills. Natasha said: "she does not know how to manage her money, does not know how to fill out a job application on her own, and gets overwhelmed with any little problem that comes her way." Her lack of life skills also made it difficult for her to keep a job or to look for a job.

In the Taylor family Mimi was also burdened by the financial responsibilities of her son David. Currently, David is living at home and is not working. His mother has to support him financially and make sure that he gets the proper treatment. She had been helping him out with his college bills and with his medical bills. She mentioned that "it is a big burden, and I won't be able to retire soon." She is sixty four and was looking forward to her retirement but plans needed to be changed to help her son. Mimi also talked about her son's inability to finish his Master's degree. She found out that he stopped going to his classes and was not going to graduate. She said that "it makes her sad because he cannot handle too much pressure." Mimi keeps supporting her son David. David's sister Sally also tried to help David by taking him to a psychiatrist and by trying to help him fill out his disability forms. Even after Sally helped David with trying to find treatment, and supported him

financially while he lived with her, David had not continued treatment and had not been able to support himself financially. Sally felt that her brother was “making the same mistakes over and over again” and that she could not continue to help him if he was not going to do what he needed to do. Sally mentioned that she had to take care of her own family and that there is “so much one can do to help out.”

In the Duran family, Caroline’s family suffered financially because of her father’s mental illness. Her father was never able to hold on to a job for too long. When her mother died, she and her sister were not able to live with their father because their father did not have a stable income and did not have a job. Caroline stated: “my father could never take care of us.” Her mother had to have many odd jobs when her parents were together because of her father’s inability to hold on to a job.

In the Lopez family, Emily and her family struggled financially because her husband was also unable to hold a job. In describing the family’s finances, Emily stated: “I never rely on him for money. My mother and I never relied on my father and now I do not rely on my husband’s salary.” Emily is not expecting her husband to be able to afford anything else for the family. She says: “we are not able to go out to eat or to go to the movies as a family because that would cost 50 dollars and we cannot afford it.”

Sally in the Taylor family mentioned that her parents started to separate when they could not handle the problems with her older brother Mike. Sally affirmed: “financial problems played a big part in my family’s problems.” For example, when the family could no longer send Mike to boarding school because the father could no longer afford it, the problems at home escalated. Referring to Mike’s behaviors when he came home from the boarding school Sally said: “He had tantrums, threw things around, and he used to get angry

at us.” When Mike reacted this way, he had problems with his father. This in turn created a stressful environment for Sally and her family. Sally concluded that Mike’s anger and emotional problems caused more problems among the family members. Thus, when Mike was home, he threatened the family’s harmony and affected the family’s unity.

Caroline in the Duran family struggled because her father “was not able to hold on to a job.” She stated:

Mom had to baby sit because dad could not keep a job. When mom died, we lived with our relatives because dad could not take care of us...we used to see my father on weekends and we could go to a restaurant and had one cup of tea only. We did not eat anything all day because he could not afford it.

When their mother died, Caroline and her sister lived with relatives because of their father’s limited financial resources. Their father was never able to take care of his daughters. Caroline and her sister survived on the money that they inherited after their mother’s death.

In summary, one of the areas of concern and distress for the families in this study was the mentally ill relatives’ inability to keep a job and their lack of life skills. In some cases, even when the mentally ill relatives were receiving disability, they were unable to manage their monies and became a financial burden on the families.

**Coping mechanisms/strategies/gaining strength.** All the caregivers talked about the different coping mechanisms and strategies the family members would use while living with their mentally ill relative. Natasha likes to travel around the world. She likes to do this without her daughter because she feels that she needs to “recharge.” She mentioned that whenever she travels with her daughter, she does not relax. Violetta is “very restless and gets bored easily”. She also “does strange things on the trip” such as talking to strangers about

very personal issues or wanting to just leave from a place whenever the family is having a good time. Natasha also avoids seeing “the friends that do not understand Violetta’s illness.” Natasha has lost many of her friends since her daughter’s illness. She stated that she only sees the people who are sensitive and understanding.

In the Taylor family, Sally mentioned that she coped with the problems at home by “hanging out with friends, and going to concerts.” When Sally was a teenager, and when her older brother’s behavior became erratic and violent, Sally started to do artwork. In addition to the photograph of herself and her siblings when they were all under the age of 10, Sally brought in an artifact. It was a silk screen painting that she had made when she was twenty. The drawing depicts people screaming and running. It looks like a flag of a revolution. She said that she made the drawings by taking pictures of herself and her brothers. There is a woman’s face on the upper left. In the center of the artwork you see two men running. Sally said that she thinks that the drawing is a symbol of how she felt in her family. The drawing made her feel that she could express herself because in her family “she had no voice.” Therefore, the drawing was something that she longed to do. She wanted freedom from the arguments at home. As a result, she devoted herself more and more to her artwork and became an art therapist. When Sally was growing up, she would go along with her brother’s Mike’s demands in order to maintain peace. When her brother Mike was selling drugs from the family’s home which was during the onset of his mental illness, he would force Sally to sell the drugs to their friends as well. Sally would succumb because “it was scary.” When he could not sleep at night, he would ask her to play video games with him all night long on a school night. Sally would go along because she said: “he would force me and I was scared.”

Sally had to “go along” with what her brother wanted her to do because she was afraid of him.

Sally’s parents coped with their son’s mental illness by sending him to a boarding school and then later on, by having him live with Sally. According to Sally, when her brother Mike was diagnosed with schizophrenia, her father rented an apartment for her and her brother. Sally had left her studies at the college to “help the family out.” Her parents felt that if Mike lived with Sally, she would be a good role model for him. Sally and her brother were in their early twenties. Sally had a job and her brother did not work. The arrangement did not work because Mike became violent and Sally ended up moving out. In addition, at that point in time, Sally’s parents divorced and her father decided to start a new life with another woman. When Sally’s father left the family, the family unit changed. Sally and her mother became the main caregivers.

Sally also talked about her inner strength. She said:

What are the positive outcomes of my experience? It gave me a drive to be successful in life and not to be like him. I said: I do not want to ever be like him. I chose art therapy because it was something that gave me insight and helped me to understand what was going on.

Accordingly, Sally felt that her strength and her success came because of what she had experienced with the mental illness in the family. She felt that her success with her career came from her struggles with her family because she did not want to be like her brothers. The experience of seeing her two brother’s mental illnesses awakened a need in her to understand and to heal others by becoming an art therapist.

Sally's mother Mimi talked about her own coping mechanisms and method of self-care. She talked about her inner belief in God which helped her on a daily basis. She said: "I enjoy my work, my friends. We go to Christian concerts together. I go to church." Mimi also added that she enjoyed going on vacations with Sally and her two grand-children. Sally has two children aged 1 and 3. She feels that her grand-children are "her pride and joy." By focusing on her grand-children, Mimi feels proud and joyful.

In the Duran family, Caroline recalled that her mother and the family in general used to use many strategies with her father in order to "maintain the peace." While describing one of her mother's strategies which she called "tricks" Caroline stated:

My mother used tricks. My father did not believe in deodorants, he thought it was just for women. She would say things like do you want to take a shower before or after dinner? She would do this so that he would not fight the idea.

When describing her own coping mechanisms and strategies dealing with her father Caroline stated:

You know I wanted to keep him happy because you learned what to say what not to say. I learned not to be too honest. If I was too frank maybe it would upset him if he did not like what I said.

Caroline recalled that her mother would tell her children to please the father in order to avoid his anger and his punishment. Caroline felt that acting the way the family was acting was not "normal". She said: "I was focused on my own coping... it was more about me surviving daddy. It was like walking on eggshells." Caroline added that her "trick" with her father was "kindness." She said: "I just used kindness to placate."

In dealing with the mental illness Caroline also talked about how she gained strength as a result of her family's experience dealing with the mental illness. When defining her inner strength Caroline stated:

It is a belief in myself. I think that sometimes living life is like developing a muscle.

I had to develop a strong muscle when I was young. I could not just depend on my parents. I had to help my mother, help my father, and protect my mother against my father. Appease my father all that work and I think that it made me strong.

Therefore, Caroline ensured that her parents did not argue by appeasing her father. She was doing that to "protect mother."

When describing her coping mechanisms Caroline stated: "the two things that helped me were humor and friends." When she talked about the joyful moments in her life amidst the sufferings she stated: "I think there was lot of joy in my life...I grew to be compassionate, open-hearted, deep, all those things... just working my character, prayer, service, benevolence, generosity, all those things... I prayed very deeply... as a result of that I was strong." Caroline felt that she had learned to have faith from her father and that she learned to have friends from her mother who was "very good at making friends." These two qualities, which were a strong belief in God and the ability to make friends, helped her deal with the mental illness in her family.

In the Lopez family, Emily had to use many strategies to deal with Mico's anger. Whenever he is about to become verbally abusive to the family and "lose control", Emily either leaves the home with her children or tells Mico to leave the home. He leaves the home and gets involved in other activities. This helps the family to "take time out" and eventually when Mico is emotionally calmer, he comes back to his family. When Mico is emotionally

upset, Emily tells her children to “stay away from daddy today because he is not feeling well.” However, sometimes, Mico cannot control his anger and lashes out at his family. Emily has left him several times but keeps taking him back when he promises to change. She is always on guard with him and watches him to determine whether he is in a “good mood” or “bad mood”. For example, when Mico is having a manic episode, Emily ensures that Mico gets out of the house and stays away from the family until his manic state has subsided or until his medications have taken effect. When describing Mico’s manic state and his mood swings Emily stated:

Even when he is manic he has both. It goes up and down. He works for five days in a row and then he sleeps for 3. He is now on his medications and he is controlling his manic states. Before he would be ranting and raving around the house. I tell him if you cannot talk then do not talk at all.

Thus, when Mico is having his manic episodes, Emily learned to tell him “not to talk at all.” This prevents his anger and his mania from escalating. She also knows that when he is going through his “manic state” it lasts a few days until he “has spent all his energy.”

Emily also added that when she learned that she was ill and there was no cure for her illness, she decided to have a living will. The will states that in case of her death, her mother will have custody of her children. Mico agreed to do this because according to Emily, “he knows he cannot take care of his children.” This was another strategy from Emily to ensure that her children would be safe in case of her death.

One way that caregivers continue to take care of their mentally ill relative was to take on more responsibilities. Natasha (Chemova family) and Mimi (Taylor family) take on many of the responsibilities for their children such as paying their bills, paying for college, or

taking care of their basic needs. For example, Natasha has to keep providing for Violetta's financial needs because Violetta "spends all her disability money as soon as she receives it." Mimi will not retire because her son does not have a job and she has to keep supporting him. In the Duran family, Caroline and her family kept helping their father out until his death. Caroline's father was not able to provide for his children once he became delusional. His children were placed with relatives and in boarding schools and lived without their father's support. Caroline took care of her father and financially provided for him at the end of his life. Emily in the Lopez family is unable to work because of her illness. Her children lack financial support and cannot afford many basic necessities. Emily gets help from her mother and her cousins in order to make ends meet. Even though she has a husband, she is solely responsible for taking care of the basic necessities of the household because her husband is not able to keep a job for a long time.

In summary, family caregivers use strategies and coping mechanisms in order to deal with the mentally ill relative's behavior and maintain peace in the household. Consequently, in order to ensure peace in the household, the caregivers changed their own behaviors. The coping mechanisms and self-care mechanisms also allowed the families to be able to live together and relieve the pressure of the burdens that the family members felt at times when the mentally ill family member's behaviors were destructive to the family unit.

**Worry about the future of the mentally ill relative.** Each caregiver talked about their worries regarding their mentally ill relative's future and their ability to take care of themselves. For example Natasha in the Chemova family stated that after she knew that her daughter had schizophrenia, she was always worried about her daughter's future. She stated: "who is going to take care of her when I am gone?" In addition, Natasha mentioned that she

worries about her daughter on a daily basis. She is always finding out exactly where her daughter is and feels worried each time her daughter delays in calling her. Natasha is always on “guard” expecting the unexpected. About 7 years ago, Violetta went to the hospital about 20 times. Each time it was for something that had happened to her. For example, once when Violetta was about 22 years old, someone called Natasha to tell her that her daughter had been “hit on the head with a bat and was hurt.” Natasha said that her daughter Violetta was doing some paper work inside her home when she heard very loud music coming from a car parked on the street. It was nighttime. Violetta decided to tell the strangers in the car (there were two men and they were drinking) to lower the music because she could not concentrate on her paperwork. One of the men hit Violetta on the head with a bat and the two men sped away in their car. Violetta was hospitalized for several days after that and had stitches on her head. There were many such incidents over the years where Natasha had to run to the hospital in the middle of the night in order to take care of Violetta.

In the Taylor family, Sally stated that she was concerned about her brothers and tried to help them out. She left college to “take care of her brother” after he was diagnosed with schizophrenia. She was also worried about her younger brother because he was not following his treatment correctly and used to take only half of the dosage prescribed to him. She also “took care of him” when she helped him to get treatment from a psychiatrist, tried to get him on disability, and then tried to help him find the right resources. Her mother Mimi, who is now living with David, is worried about her son. She worries about him finding a job and “taking care of himself.”

In the Duran family, Caroline used to worry about her father when he was living in shelters and moved around. She said: “my biggest worry was that he would die or that he

was suffering.” She was always calling him to find out how he was doing and she had become his sole caregiver after he became ill and was living in a nursing home close to her home. According to Caroline, her extended family such as her uncles and her aunts also worried about her father and helped him out financially throughout his life.

In the Lopez family, Emily could not leave her husband Mico even when she had wanted to get a divorce. She stated that each time Mico got angry and emotionally abusive she threatened to leave him. Each time, she was unable to leave him. She said: “I don’t want him to die. Each time I left him he headed down that road. I am afraid that he will kill himself.” Thus, Emily stayed with her husband because she worried about him. She felt that if she left him, he would kill himself.

In general life after the onset or diagnosis of the mental illness was when family caregivers worried about their mentally ill relative’s future. Some caregivers felt that their relative would die if they did not take care of them. The worry about their relative’s future added to the caregivers’ psychological distress.

### **Synopsis of Family Systems Theory during “life after the onset and diagnosis of the mental illness”**

In looking at the analysis for the time after the onset and diagnosis of the illness, many concepts from Bowen’s theory were used. In all four families, family caregivers continued to use the mechanisms and strategies either to ensure balance in the family or to prevent certain behaviors of their mentally ill relative. Homeostasis or keeping balance was exhibited in all four families. For instance, one family caregiver talked about how she does not see her friends anymore because she gets embarrassed about her daughter’s behavior. In order to protect herself from the embarrassment and shame she experienced from her

daughter's behavior she changed her own life and eliminated seeing her friends. Another family caregiver stated that her mother used "tricks" to help her mentally ill father do the things that were necessary for him such as taking showers in order to ensure that he was functioning properly. In the same family (Taylor family) Caroline used "kindness" to "placate" her father. This she felt ensured that he did not get angry at her mother and would not disrupt family balance.

The time after the onset of the mental illness was a time where family caregivers understood that their relative had a mental illness. During that time, family caregivers were concerned about the mentally ill relative's inability to keep a job. The issues about finance became a major concern. In trying to help their mentally ill relatives financially and by trying to help the mentally ill relative with their life skills (such as acting appropriately with others in a job situation, personal hygiene such as wearing clean clothes, taking showers, or knowing how to spend money) family caregivers tried to balance their mentally ill relative's life by continuously changing their own behaviors. Thus, their own emotional health continued to be affected because the mentally ill relative did not learn from their mistakes by making mistakes "over and over again." In the Lopez family, while describing her children's reaction to their father's mood swings and "angry episodes" Emily stated that their eldest son gets very angry at his father when his father is angry with the family. Their son starts arguing with his father which gets his father angrier. The father starts arguing and the child argues back. This in turn makes him even angrier. Usually, this kind of interaction would go on and end up with Mico losing control and breaking things in the house or becoming more and more agitated. Usually, Emily has to intervene between her husband Mico and her son in order to ensure balance by removing her son from the situation.

After the onset of the mental illness, triangulation was another mechanism that family caregivers continued to use to balance the family unit or to balance their own stress from the burdens of caregiving. For example, Natasha in the Chemova family stated that one of the reasons why her daughter continues to have difficulties in life is due to her friends who “take advantage of her.” She felt that her friends were a bad influence on her and that was the reason why Violetta kept “spending all her monthly disability checks before the month is over.” By attributing her daughter’s lack of life skills as the outcome of being with “the wrong people” she may be triangulating the problem on to a third party in order to relieve the stress that she feels. Similarly, Sally and Mimi in the Taylor family felt that the father’s absence continued to affect David’s mental illness. By stating that the father’s absence may be responsible for David’s mental illness, they were triangulating the stress that they experienced from David’s mental illness on to the father. The concept of the identified patient at this stage of the illness continued to interplay as one of the mechanisms that family caregivers used to be able to help their mentally ill relative. All the family caregivers continued to take on the stress created by the mental illness. By taking on more responsibilities in order to ensure the functioning of their mentally ill relatives, family caregivers continued to experience symptoms of anxiety and stress. The difference from the previous stage was that after the onset of the illness, the caregivers learned strategies, coping mechanisms, and methods of self-care in order to continue their caregiving duties. The methods of self-care enabled family caregivers to feel relief from the stress and burdens that they felt on a daily basis and became an important ingredient for their emotional balance.

### **Differentiation of Self and the Extended Family**

In addition to looking at the three different areas which were chronologically divided as life before the onset of the mental illness, life during the onset of the mental illness, and life after the onset of the mental illness, this study also looked at the themes that were present throughout the three different stages. Examples of such themes were the relationships of the family members with each other, psychological distress, burden associated with lack of financial support, finding the right medications, the mentally ill relative's odd or destructive behaviors, using coping mechanisms/strategies in order to maintain peace or ensure homeostasis, the effect of stigma from society, and the worry about the mentally ill relative's future. Thus, at times, the boundaries between the different chronological sections overlapped.

One general ingredient that was present throughout all the themes in analyzing the individuals' life histories was the concept of self-differentiation. Differentiation is the capacity of a family member to define him or herself apart from family unit (Bowen, 1994; Bregman & White, 2011). Looking at the individuals' levels of self-differentiation became a pivotal point in this study. This also helped to explain the effect of the extended family in the family members' lives. This in turn, shed light on the idea that in order to be able to deal with the changes that the mental illness brings to the family unit, it is also important to look at the family members' level of differentiation. By knowing the levels of differentiation of the family members involved, one can devise better interventions and get a better understanding of the burdens that each family member is carrying.

Bowen's concept of the differentiation of the self can be used to understand how each individual processes change and stress in the family unit. According to Bowen (1994), a

person who is more differentiated is a person who is not as emotionally fused with his or her family of origin and is more autonomous. That person will be able to handle change and stress better than one who is fused with their family of origin and has difficulties separating their thoughts from their feelings.

Another factor that determines the capacity to change is connected to the level of differentiation found in individuals in previous generations (Nickols, 1984). The idea of differentiation also states that families fall within a certain level of differentiation that may be either a little advanced or a little delayed in maturity, compared to their parents and grandparents. Usually, the children marry people who are in a similar range of differentiation as their own. If individuals are less differentiated and continue to have children that are less differentiated, they will be less equipped to deal with crisis and less willing to do so. Consequently, less mature individuals will be more resistant to change and less able to maintain balance or homeostasis in the family (Bowen, 1994). Therefore, the more emotionally mature one is the easier it would be for that person to assimilate change and maintain balance within the family unit.

Bowen (1994) created a differentiation scale that provides mental health providers with a scale to measure the level of differentiation of an individual (n.d. Ideas To Action, retrieved on 07/3/2013). This scale was used to look at the different levels of differentiation of the family caregivers in the four families which aided in assessing their level of emotional maturity and their ability to maintain homeostasis while dealing with the changes that the mental illness created in the family unit. In looking at the four families in this study one can see that each family had a different way of coping with the mental illness. In addition, the

level of differentiation of each family caregiver determined the manner in which he or she dealt with the psychological distress and burden created by the mental illness.

In the Chemova family, Natasha had a very difficult time accepting the mental illness of her daughter. She kept hoping that her daughter was simply adjusting to a new culture. Natasha's parents were born in a small town in Russia. Her mother Vanya and her father Euri got divorced in communist Russia when Natasha was only 6 years old. Then her mother remarried and had another son. Her step-father died from an illness when Natasha was 12 years old. Since then, Vanya (a pseudonym for Natasha's mother) has been living with her son. According to Natasha, her mother is still in denial and thinks that Violetta will stop taking the medications someday. Each time she sees her grand-daughter Violetta when she visits from Russia, she tells Natasha: "I don't see anything wrong with my grand-daughter. When is she going to stop taking her medications?" According to Natasha her mother is "upset and ashamed." Her mother also blamed Natasha for her grand-daughter's illness and told Natasha "how did this happen?" "What did you do?" This was something that really disturbed Natasha who stated that she feels like she has a "big burden on her shoulders." She also stated that she is constantly worried about her daughter. Since her daughter was diagnosed about 6 years ago, Natasha feels that she is "drained."

Natasha's quality of life has changed since Violetta's diagnosis of the mental illness. Her stress level is also higher. She stated: "I cannot relax, I cannot rest, and it is a never-ending problem." Natasha may be close to her mother on the differentiation scale because she first had a lot of difficulties accepting her daughter's mental illness and presently cannot separate herself emotionally from her daughter's problems. She also blames herself at times. While talking about Violetta's mental illness, Natasha stated: "I blame myself all the

time...maybe I was not a good mother. What did I do wrong?" Natasha has accepted the fact that her daughter has a mental illness. However, she is still unable to separate emotionally from her mother's criticisms and from her feelings of shame and guilt about Violetta's mental illness. Vanya her mother, hides the mental illness from her extended family (her sister, her daughter in law, and her brothers) and hopes that her grand-daughter "will stop taking her medications" even after being told that Violetta will need to take her medications for the rest of her life because she becomes delusional without them.

In comparing Natasha's and her mother's level of differentiation, Natasha may be a little higher than her mother on the differentiation scale. The fact that Natasha cannot separate herself from her mother's criticism and feels that somehow the mental illness is her fault, demonstrates that Natasha is having difficulties differentiating herself from her family and that her level of differentiation is close to her mother's level of differentiation. Speculating Natasha's level on the scale of differentiation, she would be somewhere in the range between 50 and 60. However, Natasha would probably fall in a higher level than her mother. Natasha has accepted her daughter's mental illness while her mother continues to deny it and blames Natasha's upbringing. Natasha also has another son who according to Natasha "tries to avoid Violetta whenever Violetta visits the family in Russia." Natasha said that her son: "feels ashamed and cannot take Violetta's strange behaviors." Therefore, Violetta's sibling may also be close in range to his grandmother and his mother's scale of differentiation. According to Bowen (1994) individuals who are less differentiated are more resistant to change.

The Taylor family is also a family where the family caregivers had difficulties with their emotions and the members displayed a low level of self- differentiation. For example,

according to Sally, her parents used to “be rich” when they lived on the east coast and were part of a family business. However, they left the family business and the father started his own business. For this reason, they left the east coast and settled in another state.

Unfortunately, the father’s business according to Sally “went under.” When the financial situation for the family worsened, the mental health of the family was also affected. Initially, when the family first moved to another state and when the father’s business was still running, the family could afford a boarding school for Mike. During that time with Mike in boarding school, the tension in the family was minimal. Once the father could no longer afford boarding school and Mike was at home, the family problems escalated. The father was not able to deal with the son’s mental illness over the years and eventually started another relationship and left the family. This according to Sally created “a lack of communication” between the father and his children. Once the father left the family and remarried another woman, he was no longer part of the family unit.

When describing her present family relationships Sally stated: “We are not on good terms. My parents cannot communicate well about their children. My father and I are not talking anymore. I had asked him to come at a different time for my marriage because my mother was coming... right now they are not talking.” Hence, Sally did not invite her father to her own wedding and told him to come at a different time because her parents were not talking to each other. Her father has been upset with her since then and has not come to visit her after the marriage. Sally feels that her mother is still angry at her father for “abandoning” the family and her mother Mimi also feels that her second son David’s mental illness was the result of the divorce. Sally also feels upset with her father for “cheating” on her mother while still married to her. Sally’s level of differentiation may be close to her mother’s level.

They both feel emotionally hurt from Sally's father's behavior and they both blamed the father's absence for David's mental illness because they felt that David did not have a father figure when he was growing up. The divorce happened when David was still an adolescent. Mike was diagnosed with schizophrenia while the parents were still married. At that time, the parents had agreed that Mike needed to take the medications but were against him getting any therapy. Sally stated: "they did not believe in counseling." After the parent's divorce, their second son David was diagnosed with bipolar disorder. His father was not involved with the family by then. David stayed with Sally who offered to "take care of him" until he was better. According to Sally, her brother David did not "feel good with the meds so he started to take half of the dosage." He did not want to return to the psychiatrist who could have helped him to find the right dosage of the medications. Instead of continuing treatment, he left to live with his mother Mimi. With his mother, David did not take his medications and started to look for work instead. However, he has been unable to get a job and has recently agreed to see a psychiatrist. Her brother David, like Mike did not want to see a therapist. They both followed in their parents' footsteps by believing that therapy was not helpful.

In that respect, Sally seems to be more differentiated than her parents and her brothers. She agreed that her brothers needed therapeutic help. She also felt that "there is only so much that I can do" after she kept trying to help her brother David get psychiatric help. She said that she wanted to help but that her brother was not cooperating. Mimi and her son David both seem to be on the same level of differentiation. They are both resisting change. Mimi believes that her son just needed a "good male role model" and that the reason he had a psychotic breakdown was because he "had too much pressure and started to take

Adderall.” Mimi is unable to separate herself emotionally from her feelings associated with the divorce.

Sally is more open to change and is more differentiated from her nuclear family. She is now a therapist and understands the implications of a mental illness. One of the reasons for Sally’s level of differentiation may be the result of living on her own away from her family, getting married and starting her own life with her two children and her husband. Sally stated that after trying to help her two brothers she had to set some limits because “they had to help themselves.” She is learning to set healthy boundaries. Her brother David, on the other hand has not been able to make a break with his family of origin. He also believed like his mother that he did not need any therapy. He started living with his mother when he had a psychotic breakdown about two years ago. He does not have a job and he is reluctant to apply for disability. Mimi has not been able to implement any changes to keep homeostasis in the family. Her son David continues to depend on her. Mimi and her son are having difficulties with changing their behavior to accommodate the implications of the mental illness. Sally mentioned that after two years of trying out other things they are convinced that they have to make some changes and have finally agreed that David needs to be medicated. As such, Sally and her mother may also range between 25 and 60 but Sally may be at the higher end whereas her mother and her brothers may be at the lower range.

In the Duran family, Caroline and her family were no longer having difficulties because of the father’s mental illness. Until then, Caroline and her family had only seen a person who would get enraged quickly and would have other symptoms of his illness such as delusions. When her father was finally on the “right medications” he was another person. Caroline felt that experience had healed her.

Caroline's parents were both born and raised on the east coast. Her family was highly educated. When her father started to show symptoms of his illness, her mother left him. When Caroline describes her childhood with her parents, she recalls all the arguments and her father's aggressive behavior. It seems that Caroline's mother was able to separate herself from her father and was able to make the changes in the family to keep her family safe. Caroline described her as a loving mother who "sent me to good schools and took very good care of us." Caroline mentioned that her sister had a difficult life until she got therapy and that her sister "used to get enraged in relationships." At that point in time, Caroline's sister was having difficulties with controlling her emotions and was drinking heavily. She changed after she started healing emotionally through therapy. Caroline felt that perhaps her sister had been more affected than her with their mother's death because she was only 12 years old when her mother passed away and needed her mother more. She also felt that her sister was not able to control her emotions and became enraged as her father did. She may have been unable to separate herself emotionally from her family history. By getting therapy in her thirties, Caroline's sister was finally able to let go of her addiction to alcohol and control her anger. Caroline felt that she was also affected by her family's history because she said she would always "over-react" and she did not want to "be like father." Caroline felt that the reason that her sister and she were able to heal was because she and her sister had "a ton of therapy." Caroline said that at the end of her father's life when he was on his deathbed, she was able to forgive her father and heal. She said: "I was with him and I held his hand and it was a beautiful peaceful death." Caroline is able to think without getting emotional about her life with her father. Family systems would define her and her mother high on the differentiation scale. They managed to be functional and were able to make changes.

Change was possible in her family because her mother did not hesitate to divorce her father. Her father, on the other hand, was not as well differentiated. He was unable to separate himself from her mother and never remarried. Consequently, both Caroline and her sister managed to heal from the pain and suffering that they experienced from their past. If one looks at their life course one can speculate that Caroline's mother was probably in the high range and could have been on the 50 and above range. Her daughter Caroline also seems to fall in that range. Caroline's sister was probably in a lower range perhaps the one ranging from 25 to 50 but has managed to differentiate herself through self-exploration and therapy.

In the Lopez family, Emily describes her own family as "always there." Her extended family such as her mother, her siblings, and her cousins all have played an integral part in filling the gap left by her husband Mico's mental illness. Emily's mother is very supportive and helps Emily create the necessary boundaries with Mico. She is the one who never wanted her daughter to marry Mico because she said that: "he is trouble." When Mico gets manic it is Emily's mother who takes care of her grand-children. Emily is also well differentiated and seems similar to her mother. Emily does not usually lose control of her emotions as opposed to Mico. In describing Mico's life, Emily said:

The only thing I know about his childhood is what he told me. He never had a relationship with his father. He hides a lot from his family. He is ashamed. His aunt does not know anything about him. He got taken away from his mother because when he was five years old he was left for days alone. He was starting fires so they took him into state custody. Mother was always in and out of his life. But never a mother that cared for her son. He stayed in state custody. His dad threw him against the wall when he was two. After that his parents got divorced. Then he was put in

state custody...school was hard because his learning disability was intense. No one helped him. They would just pass him to the next grade. He is still illiterate.

According to Emily, Mico cannot separate his emotions from his past and becomes upset easily when he talks about his parents. Emily feels that part of his problems spring from the type of life he led as a child moving from foster home to foster home. His level of differentiation would be in the lower range and closer to what his parents were. This would classify him and his nuclear family to be anywhere from 0 to 25. They seem to be fused to each other, and react emotionally to events. They seem unable to separate emotionally and do not show separate selves. Emily, on the other hand, understands that Mico needs help and makes changes to maintain the family unit. She stated that people think she is "very strong." She stated that it comes from her mother. She also said: "I was never afraid of Mico even when he gets very angry." When Mico has lost control of his emotions and gets verbally abusive she tells him to leave and tries not to react to his aggressive remarks. However, there are times when Emily gets angry and reacts to anger. She stated: "I get angry at him too, I become like him." Emily and her mother's range on the differentiation scale would most probably score above a 50. They seem to be able to separate themselves from their family dynamics when it is needed and can handle changes well. They also seem more aware of their own mechanisms to maintain balance and are not easily swayed because of their emotions.

In general, the family members' levels of differentiation affected the way they dealt with the change in the family unit which in turn affected their ability to deal and cope with the mental illness. Hence, if the caregiver was well differentiated, then he or she was more willing to make changes to maintain balance and harmony of the family unit. If the

individuals were able to separate their thoughts from their feelings then they were able to look for ways to lessen the burdens of the change created by the mental illness. They were able to feel less stressed and their coping mechanisms were effective in keeping the balance in the family unit. When the individuals were not well differentiated, then the change in the family unit created by the mental illness was a big burden and the family members were more fused with their own feelings. The fusion led to more psychological distress and an inability to find coping skills to keep the family unit intact. Thus, when people resisted the change, the stress and burden was higher.

The caregivers' level of differentiation is also the product of generational patterns. The extended family affects the way that the individual deals with his or her emotions which in turn either hinders or helps the person's level of self-differentiation. Most of the children were close to their parents in their levels of differentiation. If the pattern was to have a family who knew how to separate their thinking from their feelings, the next generation was also able to follow the same pattern. If on the other hand, the extended family was undifferentiated and was not able to separate thoughts and feelings, the next generation might also adapt the same dysfunctional pattern.

### **Summary**

This chapter presented the findings of this study. A description of the four family caregivers was presented. A thick description of the setting of the family caregivers was provided. For each family, a chronological description which centered on the mental illness as the life-course stage was provided. The findings were divided into three different areas which were: (1) Life before the onset and diagnosis of the mental illness, (2) Life during the onset and diagnosis of the mental illness, and (3) Life after the onset and diagnosis of the

mental illness. The chapter presented the mechanisms that the family members used to be able to keep homeostasis in the family. The study of the narratives for each section provided insight on the family caregivers' lived experiences.

In analyzing the narratives of the life history interviews, and of the photographs and/or artifacts that the caregivers selected to bring to their second interviews, several themes emerged. These themes helped to gain a deeper understanding of the lived experiences of the family caregivers through the different stages of mental illness. The analysis of the narratives was conducted by using family systems as a theoretical framework.

The time during the onset and the diagnosis of the mental illness was a time where the family caregivers learned that their relative had a mental illness. The process of getting the correct diagnosis and then ensuring that the mentally ill relative had the right combinations of the medications was a time where the family caregivers stated that they experienced the highest amount of burden, stress, and psychological distress. This time was also the time where the mentally ill relative had his or her first psychotic episode. During this time, the relationships of the family members started to change because of the behaviors of the mentally ill relative. Thus, the adjustment first to the symptomatic behaviors of their mentally ill relative, combined with the change in family relationships that occurred as a result of the behaviors, affected the emotional health of the families. The time after the onset was a time where the family caregivers realized that their mentally ill relatives had a mental illness. During this time, the family caregivers continued to use mechanisms to ensure that family unity was maintained. They also started to experience stigma, financial stress, and worry about the future of their mentally ill relatives. In addition, this was also the time when

the family caregivers developed strategies, coping mechanisms, and self-care methods in order to be able to gain strength from the daily stress that they experienced.

In analyzing the narratives, most of the themes that emerged corresponded to one of the three chronological areas of the study. However, some of the themes continued to affect the lives of the families throughout the three different areas. One major factor present throughout all the themes was the concept of self-differentiation which helped to define the level of maturity of the family caregivers. Bowen's scale of differentiation was used to measure the level of maturity of the individuals. By analyzing the level of differentiation of the caregivers, the coping mechanisms of the family caregivers and their levels of emotional maturity were compared. One of the main findings was that the more emotionally mature the individual was the better his or her coping mechanisms with the mental illness were. That individual was also less burdened and less stressed. In addition, the family caregivers who seemed more differentiated were less fused with their family of origin and were more able to accept the illness and make changes in their lives.

## Chapter 5: Conclusions

The purpose of this study was to better understand the lived experiences of family caregivers as a result of a relative's mental illness through three different stages of the mental illness. The mentally ill relatives were diagnosed with either schizophrenia or bipolar disorder. The study was conducted by examining narratives of the family caregivers' life histories which provided insight into their lived experiences and day-to-day realities of dealing with their mentally ill relatives. By looking at the individual realities of the caregivers, this study looked at three different stages of the mental illness which were life before, during, and after the onset and diagnosis of the mental illness. The study specifically looked at the following 6 areas in the lives of the families: (a) the relationships of the family members with each other, (b) the family's relationship with society including stigma because of the mental illness, (c) the family's finances, (d) the family's emotional health; (e) help from mental health providers, and (f) the family's coping skills and its methods of self-care (gaining strength, faith).

Looking at the time before the onset of the mental illness, one can see that the mechanisms of keeping balance or homeostasis (Bowen, 1994) are not a major concern during that time. The family was more balanced and the family conflicts common at later stages did not exist. The mentally ill relative was not showing any overt symptoms of the illness.

When describing the time before the onset or diagnosis of the mental illness, caregivers remembered the past as the "good old days." They talked with sadness about the "good qualities" of the mentally ill relative. The sadness came from remembering how the mentally ill relative used to be before the illness. Talking about that time also reminded

them of how much their life had changed since then. Family caregivers experience grief and loss (Rose et al., 2006) as a result of their relative's mental illness. The grief and loss comes from feelings of having lost the mentally ill relative to the illness. The grief is also the product of the realization that the mentally ill relative will never again be the same. In constructing their life histories, one can see how each caregiver was disappointed with what had happened to his or her loved one and to the family once he or she was diagnosed with the mental illness. The caregivers talked about their life as something that was going well and then went in another direction because of the mental illness. The family caregivers were sad at the fact that their lives had changed since their relative was diagnosed with a mental illness. Consequently, when talking about their past and when talking about the "good old days", caregivers showed a need to express their grief at the loss that they had experienced as a result of losing their relative to the mental illness.

During the onset of the mental illness, family caregivers were trying to maintain homeostasis or balance (Bowen, 1994) in the family unit. The family unit was unbalanced because of the symptomatic behaviors of the mentally ill relative which in turn caused emotional distress. At times, the mentally ill relative's behaviors were "odd and destructive." The family caregivers did not understand the reason for the change in their relative's behaviors which caused much confusion and stress. The change in the mentally ill relative's behaviors caused family members to change their own behaviors. They experienced a change in their daily routines which at times impacted their own jobs and emotional health.

During the onset of the mental illness when the mentally ill relative was diagnosed with the mental illness, some family caregivers had difficulties accepting the mental illness as well as understanding the implications of the mental illness. Some caregivers went

through denial about the diagnosis. Other caregivers triangulated the pressures that they felt from the mental illness onto another person or to another reason which allowed them to feel balanced.

During the onset of the mental illness, in order to balance the stress and burden created by their relatives' mental illness, family caregivers assumed the role of the identified patient. Bowen (1994) describes the identified patient as the person in the family who takes on all the pressures in order to balance the family unit. The identified patient absorbs all the stress to ensure balance (Bowen, 1994). In all four families, a family caregiver took on much of the stress of the mental illness. Most of family caregivers in this study developed symptoms of depression, anxiety, or problematic behaviors which impacted the family caregiver's emotional health. By taking on the pressures, the family caregivers ensured family homeostasis.

During the onset of the mental illness, the caregivers also experienced much stress and burden in the process of finding the right medications and the right dosage of the medications for their relatives. In most cases, there was a period of adjustment to the medications and accompanying side effects. The family caregivers talked about the psychological distress that they experienced as a result of the physiological changes that their relative experienced as a result of being medicated. Most caregivers also talked about their difficulties with medical providers when trying to find proper treatment for their mentally ill relative. In general, during this time, the caregivers talked about needing more support to understand the symptoms of the illness, and to learn ways to cope and deal with the mental illness on a daily basis.

After the onset and diagnosis of the mental illness, the caregivers continued to face many issues related to living with their mentally ill relative. Family caregivers continued to ensure that the mentally ill relative was functioning in society. The caregivers talked about their continuous difficulties with their relationships with each other. During this stage, family members in general used many strategies to help their mentally ill relative with their daily tasks in order to ensure that he or she was functioning.

The caregivers as the identified patient also continued to be important after the onset of the mental illness because the mentally ill relative although stabilized on medications continued to exhibit odd behaviors. In order to deal with the stress caused by the mentally ill person's behavior, family caregivers changed their own behaviors and took on the responsibilities as well as the pressures that came about because of the mentally ill relatives' behaviors.

While describing their lives after the onset of the mental illness, the caregivers talked about the shame and stigma they experienced because of the behaviors of the mentally ill relative especially in public places or in society in general. Some caregivers felt stigmatized by people who did not understand mental illness. Sometimes, the family was blamed for the mentally ill person's illness.

Furthermore, the families in this study were all affected financially by their relative's mental illness. One of the reasons why the mentally ill relative could not hold on to a job was due to lack of life skills. The mentally ill relative sometimes had difficulties managing his or her money, or behaved inappropriately in a work setting. Thus, the symptomatic behavior of the illness together with the lack of life skills (personal hygiene, managing self and finances) made it difficult for them to keep their jobs. This in turn, affected the

family's finances. In order to deal with the financial problems, most of them supported their mentally ill relative or helped them out financially which again was another method of maintaining balance or homeostasis.

Finally, one of the areas of major concern for the family caregivers after the onset of the mental illness was their worry about the mentally ill relative's future (Rose et al., 2006). In this study, family caregivers worried about "who will take care" of their mentally ill relative if they are no longer living or able to do so. Hence, this was a major concern for the caregivers which added to the psychological distress and burden that they were experiencing in their daily lives.

After the onset of the mental illness, family caregivers realized that in order to ensure the family's functioning and especially the functioning of the mentally ill relative they needed to take care of themselves. During that time, most family caregivers started to use coping skills and methods of self-care in order to ensure their own emotional and physical well-being. These mechanisms were important for the family caregivers for it allowed them to gain strength, to recharge, and to be able to continue their duties of caretaking. Hence, the coping mechanisms which included strategies used by family caregivers, and their own methods of self-care and gaining strength were important for homeostasis of the family unit. The coping mechanisms and strategies used by the family caregivers were important to ensure the well-being of their mentally ill relative as well as their own emotional and mental health.

This study also looked at the level of differentiation of each family caregiver and compared it to the level of differentiation of their family of origin. Consequently, the level of differentiation of the family members in this study was an important ingredient in looking

at the family caregivers' coping skills and their ability to make necessary changes in the family unit when dealing with mental illness. According to the findings in this study, the individuals who were less differentiated and less emotionally mature, seemed to be more resistant to change and less able to maintain balance or homeostasis. Therefore, the more emotionally mature one was, the easier it was for that person to assimilate change and maintain balance within the family unit. At the same time, the family caregivers who were less emotionally fused were also able to have a more objective vision of day-to-day lived experiences with their mentally ill relative.

Based on the findings of this study, the caregivers of the relatives diagnosed with schizophrenia and bipolar disorder go through different sets of experiences at each stage of the mental illness. Knowledge about the stages of the mental illness can help create more effective interventions. Hence, interventions for the families of the mentally ill can be devised according to the corresponding stage of the mental illness. In addition, for each stage, interventions can be targeted to help families understand their own levels of differentiation and the way it will interplay in their own process of change.

Looking at prevention and treatment according to the stage of the mental illness can help providers create better interventions. Before the onset and diagnosis of the illness, the caregivers were usually unaware that the person had a mental illness because in general, the onset is usually after the age of 15. During that time, the caregivers did not need any interventions to help them deal with the mental illness because their relative had not yet displayed the symptoms of the illness.

During the onset and diagnosis of the illness, the caregivers' needed more help and support. During this time, the family caregivers could have benefited from interventions and

programs geared to help families learn more about the mental illness, its symptoms, and its effect on the mentally ill person's cognitive and emotional functioning. This would also have been the time to help the family caregivers understand the change that can occur in their relationships with each other, and the reasons for the mentally ill relative's changing and odd behaviors which may have come about because of the effects of the mental illness.

Interventions and treatment with medical providers that include information about the type of drugs that are commonly used and their side effects could have been beneficial for the family caregivers during the onset of the mental illness.

After the onset of the mental illness, the caregivers began to understand that their relative was suffering from a mental illness. They were using their day-to-day coping mechanisms in dealing with the mental illness and ensuring that the family unit remained intact. They were trying to adjust to their relative's illness by continuing to use the strategies that worked for them in the past and by adjusting to all the different areas such as their own work schedule, their finances, and their social and family life. At that stage in both disorders, if the person was medicated the symptoms of the illness may have reached a period of stabilization. The caregivers may have become more accustomed to the "odd behaviors" of the relatives. Therefore, interventions at this stage would have focused on understanding the continuous odd behaviors that the mentally ill person might still exhibit, and the financial stress and burden that the families continued to experience. At this stage the interventions could have included teaching different strategies and coping mechanisms, and providing families with resources to help with the caretaking burdens.

In addition, after the onset of the mental illness, families might have also needed help and support in order to deal with the shame and stigma they may have experienced while

living in society. Moreover, after the onset of the mental illness, interventions could have been focused on helping caregivers with their worry for the mentally ill relative's future and on finding ways that family caregivers could continue to get the help and support that they need.

Based on the findings in this study, the time during the onset of the illness which is when the mentally ill relative had his or her first psychotic episode was laden with intense psychological distress, stress, and burden for the family caregivers. This is the time when secondary prevention becomes important for it is when psychosis is present. The first episode opens the door for an opportunity to prevent the neuroanatomical, neuropsychological, clinical, and functional outcomes of the progression of mental illness (Berk et al., 2007). This is important information for the family caregivers and could have helped them better understand their relative's mental illness and consequently, also helped them understand the importance of avoiding further damage by ensuring the proper combination of pharmacological and psychosocial treatment.

By getting more information and by understanding that with a mental illness, the diagnosis for the disorder cannot be made until mania (in the case of bipolar disorder) and psychosis (in the case with schizophrenia) are present, the caregivers might have been able to understand the delay in the diagnosis of bipolar disorder and schizophrenia. According to the findings of this study, the time during the onset was a stressful time for the family caregivers and by getting more information about the stage of the mental illness and about ways to prevent recurrent episodes, family caregivers might have experienced less stress and psychological distress. The family caregivers of the mentally ill would have felt more included in the treatment if they had been more aware of the physiological as well as the

psychosocial components of a person's life when affected by a mental illness. Moreover, if family caregivers had looked at the mental illness as a progressive illness, they might have felt more prepared to cope with the burdens associated with the tasks of taking care of their mentally ill relative and the uncertainty that accompanies the stress and burden might have been diminished.

After the onset of the mental illness, even when the mentally ill relatives were medicated and stabilized, they continued to exhibit behaviors that disrupted the family's life. Understanding that the "odd and strange behaviors" of the mentally ill relative may be present throughout their lives because of the effect of the mental illness, would have also helped family caregivers understand that the behaviors of their mentally ill relative and their thinking processes may be affected by the disorder even after they are medicated and stable. This might have also helped the family caregivers understand the long term effect of the mental illness. After the onset of the mental illness, interventions could have been devised to assist family caregivers find better coping mechanisms as well as better methods of self-care.

In summary, each stage of bipolar disorder and schizophrenia is different and treatment targeting the specific areas according to the challenges encountered at each stage might have helped family caregivers obtain interventions necessary for each stage of the illness. Looking at the mental illness as a progressive disorder might have helped family caregivers and providers to look for more effective ways to prevent relapse and further progression of the illness. This in turn might have helped family caregivers have a better quality of life. By getting proper support, and appropriate interventions, the family caregivers would have felt less burdened and more supported by society.

### **Implications for Future Research**

This study can serve as a catalyst for understanding the lived experiences of the family caregivers dealing with schizophrenia and bipolar disorder. It also stresses the idea that each stage of a mental illness is different and the caregivers' stress burdens, and coping mechanisms for each stage are also different. More research in this area would target the types of interventions that would be needed at each stage. It is important to understand that a brain disorder is a complex matter and the research connected with the functioning of the human mind is constantly evolving, changing, and perfecting itself with time.

In general, current research in the area of family caregivers of the mentally ill focuses on interventions for the mentally ill patient, while neglecting the importance of the vital role that the caregivers play in the treatment of their ill relatives. It is evident that in order to better assist the mentally ill population, society needs to offer more support and assistance to the family caregivers. This narrative study attempted to address this gap in the literature by providing insight into the life histories of family members caring for relatives diagnosed with either schizophrenia or bipolar disorder through three different stages of the disorder.

In hindsight, it would also be important to look at the learning and strength that the caregivers acquired as a result of the caretaking. Much of the research has been focused on the burdens and psychological distress but not enough on the positive aspects gained from that experience. In this study, three of the caregivers talked about the strength that they gained as a result of their struggle with the mental illness of a relative. More research in this area can help the families with a mentally ill relative see the silver lining behind the cloud. By sharing and studying the positive outcomes of caregiving for mentally ill relatives,

providers can include the knowledge gained from such studies to help caregivers enhance the quality of their lives.

This study aimed to look at the lived experiences of family caregivers through the different stages of two mental illnesses, schizophrenia and bipolar disorder. It aimed to provide an added dimension to the understanding of the two mental illnesses and their effects on different areas of the family caregivers' lives. This may open doors for more studies geared to understanding how the diagnosis and stage of other mental illnesses contribute to burden, stress, and psychological distress. If information about the stage of the mental illness is included, then family caregivers may be able to gain more understanding of the behaviors and difficulties accompanying each state. Consequently, the interventions would also include the coping mechanisms and skills needed at each stage. The field is vast and every step can help bring a little more clarity and more hope for a better future. This study aimed to open the gateway to many unanswered questions for families entrusted with the difficult task of caring for a mentally ill relative. More studies in this area would improve services for the families of the mentally ill as well as offer providers the tools for devising better interventions.

At the present, if a person is over 18 years of age, he or she can choose to exclude the family caregivers from treatment because at 18 one is considered to be a competent adult. However, if there is a way to include family members in every facet of treatment, then the gap that exists today between the time when the person is finally diagnosed with the mental illness and the time that family caregivers experience the onset of the mental illness can be diminished. By being informed earlier and by being included in treatment, caregivers can begin to understand the problems associated with the mental illness and avoid the desperation

they feel when the symptomatic behaviors get out of control. This study may enhance the interventions geared to helping the mentally ill and their families by providing them with an emic view of the family caregivers' lived experiences.

When devising interventions for the mentally ill and their family caregivers, it is also important to look at the cultural backgrounds of the family being helped. Stigma against the mentally ill differs in each culture. In some countries, people can openly discriminate against the mentally ill. In some developing countries, the government does not provide any financial help to the mentally ill and families with limited income become more burdened because of lack of finances to support their mentally ill family member.

Hopefully, with more awareness and more studies in this area, the growing number of family caregivers who are part of our society and our world can someday find more support and understanding. This in turn can help decrease the stigma associated with mental illness as well as its accompanying stress and burden. More awareness and studies in this area would also help family caregivers to feel less shame about having a mentally ill relative and feel more integrated within society. Thus, instead of feeling isolated, the family caregivers would feel part of a larger society, one that is not afraid of the mentally ill, one that does not blame the families for the mental illness at times, and one which knows that mental illness is part of our world and part of everyone's struggle.

In the long run, better interventions for the family caregivers of the mentally ill would help prepare families by providing them with better tools in order to deal with the mental illness. Better interventions tailored to the stage of the mental illness and more support could also help family caregivers use more effective strategies and better methods of self-care. Ultimately, family caregivers of the mentally ill may experience a better quality of life

If we ponder deeply into what systems are really about, by enhancing the lives of the families of the mentally ill, we are helping society at large. Society is composed of people with mental illness and we are part of that system. Therefore, by understanding the burden faced by the millions of families around the world, we can all relate to something crucial in the human experience which is to make our lives a little easier and thus make other people's lives easier. In doing so, we are only helping ourselves and the world we live in for generations to come.

*A poem for the Parents of a Mentally Ill Child*

*To all the ones who are suffering*

*In silence from the bond of love*

*For the one who has*

*stepped into unknown territories.*

*For the ones who never sleep too deeply*

*for if they do, a calamity may*

*darken their days over and over again.*

*You recall,*

*the time when you felt*

*that life was smiling at you*

*and the being in your arms*

*was going to continue to live*

*like you do and follow*

*the footsteps you had envisioned.*

*For so long,*

*You have changed that vision.*

*You have adjusted to the new reality.*

*Sometimes you want to know*

*what is his world really like?*

*It feels like he is looking*

*through clouds of confusion,*

*confusion to you but not to him*

*You learn to live*

*partly in his world*

*to take him out of his.*

*You learn to enjoy the*

*moments when his eyes*

*are like they used to be,*

*when he was an infant*

*innocent and pure,*

*just waiting to live*

*the wonders of the day,*

*while he held your hand*

*and now you know*

*that you may have to hold it forever*

*and dread the day*

*when your hand can no longer hold his*

*Reshma Kamal*

## References

- American Psychiatric Association, (2000). *Diagnostic and statistical manual of mental disorders* (4<sup>th</sup> ed., text revision). Washington, DC: Author.
- Bateson, G., Jackson, D., Haley, J., & Weakland, J. (1956). Toward a theory of schizophrenia. *Behavioral Science*, 1, 251-264.
- Berk, M., Hallam, K., Malhi, G.S., Henry, L., Hasty, M., Macneil, C., ... McGorry, P.D. (2010). Evidence and implications for early interventions in bipolar disorder. *Journal of Mental Health*. 19 (2), 113-126.
- Bipolar Disorder, NIMH, retrieved on line on 05/03/2011 from <http://www.nimh.nih.gov/health/publications/bipolar-disorder/complete-index.shtml>
- Bipolar Disorder, retrieved on line on 04/17/2013 from <http://medical-dictionary.thefreedictionary.com/bipolar+disorder>
- Bowen, Murray (1994). *Family therapy in clinical practice*. Lanham, Maryland. First Rowman & Littlefield Publishers, INC.
- Bregman, O.C., & White, C.M. (2011). *Bringing systems thinking to life: expanding the horizons for Bowen family systems theory*. New York, London. Routledge. Taylor & Francis Group.
- Bruner, J. (1990). *Acts of meaning*. Cambridge, MA: Harvard University Press.
- Camic, P.M., Rhodes, J.E., & Yardley, L. (2003). *Qualitative Research in Psychology: Expanding Perspectives in Methodology and Design*. American Psychological Association, Washington, DC.
- Chang, K.H., & Horrocks, S. (2006). Lived experiences of family caregivers of mentally ill relatives. *Journal of Advanced Nursing*, 53 (4), 435-443.

- Chiu, M.Y., Wei, G.F., & Lee, S. (2006). Personal tragedy or system failure: A qualitative analysis of narratives of caregivers of people with severe mental illness in Hong Kong and Taiwan. *International Journal of Social Psychiatry*. Vol 52(5): 413-423.
- Clandinin, D.J., & Connelly, F.M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Jossey-Bass.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research, 3e*. Thousand Oaks, CA: Sage.
- Corrigan, P. W., & Penn, D. L. (1999). Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*, 54(9), 765-776.
- Corrigan, P.W., & Miller, F.E. (2004). Shame, blame, and contamination: A review of the impact of mental illness stigma on family members. *Journal of Mental Health*, 13, 6, 537-548.
- Corrigan, P.W., Watson, A. C., & Miller, F.E. (2006). The impact of mental illness and drug dependence stigma on family members. *Journal of Family Psychology*, 20, 2, 239-246.
- Creswell, J.W. (2007). *Qualitative Inquiry and Research Design: Choosing among five approaches*. Sage Publications.
- Deinstitutionalization (n.d.), in Merriam- Webster online dictionary (11<sup>th</sup> ed) retrieved on 11/08/2011 from <http://www.merriam-webster.com/dictionary/deinstitutionalization>.
- Denzin, N.K. (1989). *Interpretive biography*. Newbury Park, CA: Sage.
- Doornbos, M.M. (2002). Family caregivers and the mental health care system; reality and dreams. *Archives of Psychiatric Nursing*. Vol XVI, No 1. 39-46.

- Dyck, D.G., Short, R., & Vitaliano, P.P. (1999). Predictors of burden and infectious illness in schizophrenia caregivers. *Psychosomatic Medicine, 61*,411-419.
- ECT (n.d.), retrieved on line on 10/26/2013 from <http://www.webmd.com/bipolar-disorder/electroconvulsive-therapy-ect>.
- Emic (n.d.), in Merriam Webster online dictionary retrieved on 12/09/2011 from [www.merriam-webster.com/dictionary/emic](http://www.merriam-webster.com/dictionary/emic).
- Freidman, E. (1985). *Generation to Generation: Family Process in Church and Synagogue*. New York, Guilford Press.
- Fujino, N., & Okamura, H. (2009). Factors affecting the sense of burden felt by family members caring for patients with mental illness. *Archives of Psychiatric Nursing, 23*, 2, 128-137.
- Ganguly, K.K., Chadda, R.K., & Singh, T.B. (2010). Caregiver burden and coping in schizophrenia and bipolar disorder: a qualitative study. *American Journal of Psychiatric Rehabilitation, 13*, 126-142.
- Gilbert, M. R. (2006). *The Eight Concepts of Bowen's Theory*. Falls Church, VA: Leading Systems Press.
- Glesne, C. (2010). *Becoming Qualitative Researchers: An Introduction (4<sup>th</sup> Edition)*. Prentice Hall.
- Goldman, H.H. (1982). Mental illness and family burden: a public health perspective. *Hospital and community psychiatry, 33*, 557-560.
- Goffman, E. (1963). *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.

- Greenberg, J. S., Kim, H. W., & Greenley, J. R. (1997). Factors associated with subjective burden in siblings of adults with severe mental illness. *American Journal of Orthopsychiatry*, 67, 231–241.
- Guarnaccia, P.J., & Parra, P. (1996). Ethnicity, social status, and families experiences of caring for a mentally ill family member. *Community Mental Health Journal*, 32, 243-260.
- Gubman, G.D., Tessler, R.C., & Willis, G. (1987). Living with the mentally ill: factors affecting household complaints. *Schizophrenia Bulletin*, 13, 727-736.
- Heru, A. M. (2000). Family functioning, burden, and reward in the caregiving for chronic mental illness. *Families, Systems, & Health*, 18(1), 91-103.
- Huan, X., Sun, F., Yen W., & Fu, C. (2007). The coping experiences of carers who live with someone who has schizophrenia. *Journal of Clinical Nursing*. 17, 817-826.
- Hutchinson, D., Anthony, W., Ashcraft, L., Johnson, E., Dunn, E.C., Lyass, A., & Rogers, E.S. (2006). The personal and vocational impact of training and employing people with psychiatric disabilities as providers. *Psychiatric rehabilitation Journal*, 29, 205-213.
- Ideas To Action, n.d., retrieved on line on 07/13/2013 from <http://ideastoaction.wordpress.com/dr-bowen/bowen-theory/differentiation-of-self-scal/>
- Jubb, M., & Shanley, E. (2002). Family involvement: The key to opening locked wards and closed minds. *International Journal of Mental Health Nursing*, 11(1), 47-53.
- Kelly, S., & McKenna, H. P. (2004). Risks to mental health patients discharged into the community. *Health, Risk & Society*, 6(4), 377-385.

- Kerr, M. E., & Bowen, M. (1988). *Family evaluation: An approach based on Bowen theory*. New York, NY US: WW Norton & Co.
- Kraus, J.B., & Slavinsky, A.T. (1982). *The Chronically Ill Psychiatric Patient and the Community*. Boston, Blackwell Scientific Publishers.
- Krieg, R. G. (2001). An interdisciplinary look at the deinstitutionalization of the mentally ill. *The Social Science Journal*, 38(3), 367-380.
- Kuipers, E. (2006). Family interventions in schizophrenia: Evidence for efficacy and proposed mechanisms of change. *Journal of Family Therapy*, 28(1), 73-80.
- Lefley, H.P., & Johnson, D.L. (1990). Families as allies in treatment of the mentally ill: new Directions for mental health professionals. *American Psychiatric Press*.
- Lidz, T., Fleck, S., & Cornelison, A. (1965). *Schizophrenia and the Family*. New York, International Universities Press.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
- Link, B.G., & Phelan, J.C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, p. 363-385
- Link, B.G., Phelan, J.C., Bresnahan, M., Stueve, A., & Pescosolido, B.A. (1999). Public Conceptions of mental illness: labels, causes, dangerousness and social distance. *American Journal of Public Health*, 89, 1328-1333.
- Lively, S., Friedrich, R., & Rubenstein, L. (2004). The effect of disturbing illness behaviors on siblings of persons with schizophrenia. *Journal of The American Psychiatric Nurses Association*, 10(5), 222-232.

- Maslow, A. (1943). A theory of human motivation. *Psychological Review*. Vol 50, 4, p.370–396.
- Mayo Clinic (n.d.). Catatonic schizophrenia. Retrieved from <http://www.mayoclinic.com/health/catatonic-schizophrenia/DS00863>
- Mayan, J.M. (2009). *Essentials of qualitative inquiry*. Walnut Creek, CA: Left Coast Press.
- McIntosh, B., & Zirpoli, E.R. (1982). Fighting parents' helplessness. *International Journal of Group Psychotherapy*, 32, 75-89.
- Mental Illness, (n.d). In Merriam-Webster's online dictionary (11<sup>th</sup> ed). Retrieved from <http://www.merriamwebster.com/medical/mental+disorder?show=0&t=1291746854>
- Mental Illness, NAMI. Retrieved on line on 05/03/2011 from [http://www.nami.org/Content/NavigationMenu/Inform\\_Yourself/About\\_Mental\\_Illness/About\\_Mental\\_Illness.htm](http://www.nami.org/Content/NavigationMenu/Inform_Yourself/About_Mental_Illness/About_Mental_Illness.htm)
- Miklowitz, D. J., & Scott, J. (2009). Psychosocial treatments for bipolar disorder: Cost-effectiveness, mediating mechanisms, and future directions. *Bipolar Disorders*, 11(Suppl2), 110-122.
- Muhlbauer, A.S. (2002). Experience of stigma by families with mentally ill members. *Journal of the American Psychiatric Nurses Association*, 8, 76-83.
- Muhlbauer, S. (2008). Caregiver perceptions and needs regarding symptoms attenuation in severe and persistent mental illness. *Perspectives in Psychiatric Care*, 44, 2.
- Nichols, M. (1984). *Family Therapy, Concepts and Methods*. New York. Gardner Press.
- Oliver, J., Huxley, P., Bridges, K., & Mohamed, H. (1996). Quality of life and mental health services. *British Journal of Social Work*. 26, 5, 743-745

- Ostman, M., & Hansson, L. (2002). Children in families with a severely mentally ill member-prevalence & needs for support. *Soc Psychiatr Epidemiol*, 37, 243-248.
- Phelan, J.C., Link, B.G., Stueve, A., & Pescosolido, B.A. (2000). Public conceptions of mental health illness in 1950 and 1996: What is mental illness and is it not to be feared? *Journal of health and Social Behavior*, 41, 188-207
- Potasznik, H. (1995, June). Psychiatric symptoms, social support, and coping: Potential predictors of burden in caregivers of the mentally ill. *Dissertation Abstracts International*, 55
- Veague, H. B. (2007). *Psychological disorders: schizophrenia*. Infobase Publishing.
- Rammohan, A., Rao, K., & Subbakrishna, D.K. (2002). Religious coping and psychological wellbeing in carers of relatives with schizophrenia. *Acta Psychiatr Scand*. 105, 356-362.
- Reinares, M., Colom, F., Rosa, A.R., Bonnín, C.M., Franco, C., Solé, B., ...Vieta, E. (2010). The impact of staging bipolar disorder on treatment outcome of family psychoeducation. *Journal of Affective Disorders*, 123, 81-86.
- Reupert, A., & Mayberry, D. (2007). Families affected by parental mental illness: A multiperspective account of issues and interventions. *American Journal of Orthopsychiatry*, 77, 3, 362-369.
- Reissman, K. R. (1993). *Narrative analysis*. Sage Publications.
- Rogers, C. (1959). A theory of therapy, personality, and interpersonal relationships, as developed in the client-centered framework. In S. Koch (ed), *Psychology: a Study of Science, Vol III. Formulations of the Person and the Social Context*, New York: McGraw-Hill.

- Rose, L.E., Mallinson, R.K., & Gerson, L.D. (2006). Mastery, burden, and areas of concern among family caregivers of mentally ill persons. *Archives of Psychiatric Nursing*, 20, 1, 41-51.
- Scheirs, J.G.M., & Bok, S. (2007). Psychological Distress in caregivers or relatives of patients with borderline personality disorder. *International Journal of Social Psychiatry*, 53, 3, 195-203.
- Schizophrenia, retrieved on line on 04/17/2013 from  
<http://www.nimh.nih.gov/health/publications/schizophrenia/what-is-schizophrenia.shtml>
- Schizophrenia, retrieved on line on 10/19/2013 from  
<http://www.everydayhealth.com/guide/schizophrenia/progression.aspx>
- Seeman, M. V. (2009). The changing role of mother of the mentally ill: from schizophrenogenic mother to multigenerational caregiver. *Psychiatry: Interpersonal and Biological Processes*, 72(3), 284-294.
- Sherman, M.D., & Carothers, R.A. (2005). Applying the readiness to change model of implementation of family interventions for serious mental illness. *Community Mental Health Journal*, Vol. 41, No 2.
- Strakowski, S.M., Keck, P.E., McElroy, S.I., West, S.A., Sax, K.W., Hawkins, J.M., ... Bourne, M.L. (1998). Twelve-month outcome after first hospitalization for affective psychosis, *Archives of General Psychiatry*, 55, 49-55.
- Stuart, G.W., & Sundeen, S.J. (1995). *Principles and Practice of Psychiatric Nursing*. St. Louis: Mosby.

- Suresky, M., Zauszniewski, J. A., & Bekhet, A. K. (2008). Sense of coherence and quality of life in women family members of the seriously mentally ill. *Issues In Mental Health Nursing, 29*(3), 265-278.
- Tardive Dyskinesia (n.d) retrieved on 10 26/2013 from <http://www.tardivedyskinesia.com>.
- Peternelj-Taylor, C. (2008). Criminalization of the mentally ill. *Journal of Forensic Nursing, 4*(4), 185-187.
- Toseland, R.W., Rossiter, C.M., Peak, T., & Smith, G.C. (1990). Comparative effectiveness of individual and group interventions to support family caregivers. *Social Work, 35*, 209-217.
- Torrey, E.F. (1995). Jails and prisons-America's new mental hospitals. *American Journal of Public Health, 85*(12), 1611-1613.
- Velakoulis, D., Woods, S.J., Wong, M.T.H., McGorry, P.D., Yung, A., Phillips, L., ... Pantelis, C. (2006). Hippocampal and amygdala volumes according to psychosis stage and diagnosis. *Arch of General Psychiatry, Vol 63*.
- Vermont family studies retrieved from [http://www.vermontcenterforfamilystudies.org/bowen\\_family\\_systems\\_theory/](http://www.vermontcenterforfamilystudies.org/bowen_family_systems_theory/) retrieved on 11/22/2013
- Winefield, H. R., & Harvey, E. (1993). Determinants of psychological distress in relatives of people with chronic schizophrenia. *Schizophrenia Bulletin, 19*, 619-623
- Yang, L. H., & Pearson, V.J. (2002). Understanding families in their own context: schizophrenia and structural family therapy in Beijing. *Journal of Family Therapy, 24*, 233-257.

**Appendix A: Interview Protocol<sup>1</sup>**

Date: \_\_\_\_\_

Time of interview: \_\_\_\_\_

Interviewer: \_\_\_\_\_

Interviewee: \_\_\_\_\_

This is a qualitative study about the lived experiences of family caregivers of a mentally ill relative. This interview will be tape-recorded.

---

<sup>1</sup> Modified from Creswell (2007)

## **Appendix B: Interview Questions**

- 1) How was your family life before the onset of your relative's illness?
- 2) How was your family life during the onset of the illness?
- 3) How is your life now after the onset of the illness?

### **Sub-questions**

- a) How was your relationship to each other before/during/after the onset and diagnosis after the diagnosis of the mental illness?
- b) How was your relationship with extended family members, friends, and co-workers before/during/after the onset and diagnosis of the mental illness?
- c) How was your emotional health before/during/after the onset and diagnosis of the mental illness?
- d) How much help did you receive from the community (friends, and health providers, and effect of stigma in society?) before/during/after the onset and diagnosis of the mental illness?
- e) How did you manage your finances before/during/after the onset and diagnosis of the mental illness?
- f) How did you cope before/during/after the onset and diagnosis of the mental illness?
- g) How did you gain strength and take care of yourself before/during/after the diagnosis/and after the diagnosis of the illness?