

THE EFFECTS OF SCHIZOPHRENIA ON THE FAMILY:
A REVIEW AND PERSONAL ACCOUNT

By

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ABSTRACT

Schizophrenia can be an extremely disabling individual disorder but it is also clear that it is a “family disorder” as well. Researchers have begun to assess the correlates and possible causes of this disorder on families in the United States as well as in other nations. This report reviews this research. Most research to date has focused on two aspects of the schizophrenia-family relationship: expressed emotion and sense of burden. Following a definitional review of schizophrenia, its history, and its treatment, this report reviews research conducted on expressed emotion (relative’s propensity to express critical, hostile, or over involved attitudes about a patient when discussing the patient’s illness with an interviewer) and sense objective and subjective of burden of care provision. A personal account is offered regarding what it was like for the writer to grow up in a family with a parent diagnosed with schizophrenia. Finally, the conclusion of this report evaluates the strengths and weaknesses of current research on the impact of schizophrenia and the family. Suggestions for future research are derived partially from the content of the personal account. These include the need for a research targeting the full family, developmentally- and contextually-appropriate theories to guide the research, and the need for more qualitative research to identify individual and family variables that should guide future empirical efforts. It is suggested that programmatic family education and counseling should begin soon after diagnosis of the disorder, be developmentally relevant, and designed to sustain family members over long periods of time.

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CHAPTER ONE

Purpose and Background

Purpose

The purpose of this report is to review and to evaluate research and scholarly literature related to the impacts of schizophrenia on family functioning. This topic was chosen due to my personal experience of growing up in a household with a schizophrenic parent. Family members agonize and endure much stress over a loved one's illness. In particular, the chronic stressors associated with the disorder have a high potential for influencing both everyday as well as long-term developmental contexts for families and individuals. Thus, the intent is to investigate the dynamics of the family context of schizophrenia. Research literature focusing on developmentally-relevant issues, particularly the impact of parental schizophrenia on children, was also targeted.

Introduction to Schizophrenia

Documentation of people experiencing psychotic episodes dates back to ancient times. These episodes could have been caused by any number of disorders, but one in particular may have been the culprit—Schizophrenia. It is one of the most debilitating mental disorders and can affect almost every aspect of a person's life.

In their review of the history of schizophrenia, Walker, Bollini, Hochman, and Kestler (2005) report that in the mid to late 19th century, psychiatrists were unaware that the symptoms of schizophrenia and other illnesses (such as tertiary syphilis) overlapped with each other (Walker et al., 2005). While antibiotics were introduced to cure many illnesses, they were of little aid to many who still suffered from psychotic episodes. This led psychiatrists to the awareness that a variety of mental disorders are marked by similar

symptoms. Emil Kraepelin (1856-1926), the medical director of Heidelberg Clinic, was the first to distinguish between schizophrenia (which he termed dementia praecox) and manic-depressive mental disorder. In his view, dementia praecox could be diagnosed by noting the evolution of its symptoms as well as its evolving deterioration over a period of months and years. He also believed that those diagnosed with dementia praecox had a poor long-term prognosis.

In the early 20th century, psychiatrists continued to refine the diagnostic criteria for schizophrenia. In 1910, Eugen Bleuler, a Swiss psychiatrist, introduced the term “schizophrenia.” The literal meaning of the word is “the splitting or tearing of the mind and emotional stability of the patient” (Walker et al., 2005, p. 180). Bleuler believed that any person suffering from schizophrenia would exhibit symptoms (disturbances of association, disturbances of affect, disturbances of attention, ambivalence, autism, abulia, and dementia) that separated the disorder from that of “multiple personality.” He created a symptom rubric that displayed these “fundamental symptoms” that persons suffering from schizophrenia displayed through all the stages of the illness. Other symptoms -- “accessory symptoms” (delusions, hallucinations, movement disturbances, somatic symptoms, manic and melancholic states) -- were also observed in some patients, but were not unique to schizophrenia and could also be found in other mental disorders.

During this same time period, Kurt Schneider was refining the diagnostic criteria for schizophrenia. Like Bleuler, he believed that “certain key symptoms were diagnostic of schizophrenia” (Walker et al., 2005, pp. 180-181). Schneider’s criteria disclosed first rank symptoms and his accounts were more detailed. Future research on diagnostic criteria was influenced by Schneider’s research on these concepts.

Current Definition and Diagnostic Criteria for Schizophrenia

The Diagnostic and Statistical Manual of Mental Disorders, (DSM-IV-TR, 2000) defines schizophrenia as “a mixture of characteristic signs and symptoms (both positive and negative) that have been present for a significant portion of time during a 1-month period (or for a shorter time if successfully treated), with some signs of the disorder persisting for at least 6 months” (p. 298). Positive symptoms include the presence delusions, hallucinations, disorganized speech, and grossly disorganized or catatonic behavior. Negative symptoms are recognized by a lack or paucity of emotions (affective flattening), of speech (alogia), or of goal-directed behavior (avolition) (DSM-IV-TR, p. 299).

Schizophrenia and other psychiatric disorders are marked by similar symptoms. The following criteria are utilized in the diagnosis of schizophrenia (DSM-IV-TR, 2000):

- A. *Characteristic symptoms:* Two (or more) of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated):
1. delusions
 2. hallucinations
 3. disorganized speech (e.g., frequent derailment or incoherence)
 4. grossly disorganized or catatonic behavior
 5. negative symptoms, i.e., affective flattening, alogia, or avolition

- B. Social/occupational dysfunction:* For a significant portion of the time since the onset of disturbance, one or more major areas of functioning such as work, interpersonal relations, or self care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).
- C. Duration:* Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1-month of symptoms (or less if successfully treated) that meet Criterion A (i.e., active phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).
- D. Schizoaffective and Mood Disorder exclusion:* Schizoaffective Disorder and Mood Disorder With Psychotic Features have been ruled out because either (1) no Major Depressive, Manic, or Mixed Episodes have occurred during active-phase symptoms; or (2) if mood episodes have occurred during

active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods.

- E. *Substance/general medical condition exclusion:* The disturbance is not due to the direct physiological effects of a substance (e.g., drug of abuse, a medication) or a general medical condition.
- F. *Relationship to a Pervasive Developmental Disorder:* If there is a history of Autistic Disorder or another Pervasive Developmental Disorder, the additional diagnosis of Schizophrenia is made only if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).

Treatment of Schizophrenia

There is no cure for schizophrenia at this time. It is a chronic disorder, so an affected individual may have to deal with a lifetime of treatment. Treatment of the disease focuses on managing the symptoms and can include hospitalization, medication, and psychosocial treatment.

Individuals that are suffering from severe hallucinations, delusions, inability to care for themselves, abusing alcohol or drugs, and/or suffering from suicidal thoughts may require hospitalization. Civil rights protections require that evidence must exist that one is a danger to oneself or others in order for hospitalization to occur. The evaluation of a mental health professional determines if either voluntary or involuntary admission is

necessary. A legal recommendation for commitment may occur based on the extent or severity of symptoms.

Medication is a critical aspect of the treatment and management of schizophrenia. Anti-psychotic medications (e.g., clozapine, risperidone, olanzapine, quetiapine, sertindole, and ziprasidone) are used to treat the positive symptoms; several drugs may have to be tried before one is found that is effective. The working goal is to find the balanced medication regimen that controls the symptoms best with the fewest side effects. Those suffering from both positive and negative symptoms may also require anti-depressants, mood stabilizers, or benzodiazepines to control catatonic behavior. After starting a medication regimen, agitation and hallucinations may start to improve within days and the delusions within a few weeks (National Institute of Mental Health, 2007, p. 10).

Individuals with schizophrenia who have been stabilized on medication may also benefit from psychosocial treatment to help them to cope with the disorder. Becoming educated about the illness can help one to establish improved communication, motivation, self-care, work, interpersonal relationships, and medical compliance on a regular basis. “A positive relationship with a therapist or a case manager gives the patient a reliable source of information, sympathy, encouragement, and hope, all of which are essential for managing the disease” (National Institute of Mental Health, 2007, p. 12).

Family members of those suffering from schizophrenia may also need support and education about the illness. Knowledge of effective coping strategies and problem solving skills may aid in protecting the affected family member against a relapse. That is, family members may create an environment that may be therapeutic for a relative who

has schizophrenia. Support groups, mental health facilities, and online services can be valuable tools for those seeking intervention techniques.

CHAPTER TWO

Schizophrenia and the Effects on Family

Expressed Emotion

Caring for a loved one suffering from schizophrenia can have a major impact on the family unit. One area that has a strong relation to schizophrenics and their key relatives is “expressed emotion.” Gumber and Misra (2004) define expressed emotion (EE) as “A measure of the relative’s propensity to express critical, hostile, or over involved attitudes about a patient when discussing the patient’s illness with an interviewer” (p. 196). Studies on expressed emotion focus on the level of EE and whether or not the level plays a role in relapse of patients. Some research briefly touches on cultural influence, ethnicity, and geographic location of schizophrenics and the effect these factors may have on the level of EE among their families. The construct of expressed emotion has typically been assessed with two methods. The first is the Five Minute Speech Sample which “elicits a response from the patient’s key relative. This task is aimed at identifying the respondent’s attitudes and feelings about the patient as well as perceptions of the quality of their relationship” (Gumber & Misra, 2004, p.197). The second measure is the Camberwell Family Interview (CFI). This method consists of audiotaped interviews of key relatives. The narratives are then rated (Likert scale) on criticism, frequency count of critical comments, and emotional over-involvement (EOI). Warmth, expressions of sympathy, empathy, concern for the patient, expression of enjoyment, pride, and admiration of the patient are also rated (Mueser, Bellack, Wade, Sayers, Tierney, & Haas, 1993, p. 341).

Gumber and Misra (2004) conducted a study in New Delhi, India, to gain an “understanding how the construct of EE operates within the family, both from the perspective of the key relatives and the patients as well as to investigate the coping mechanisms within the family and the effects it has on the general health and the quality of the patient’s life” (p. 196). The clinical sample consisted of 15 schizophrenic patients (six male and nine female); their age range was 20 to 50 years and the duration of their illness was 2 ½ years to 25 years (p. 197). In order to assess the EE level of familial environment, 15 family members with the highest contact with the patient were interviewed. “In five cases the key relative was the mother, in five cases it was the father, in two of the patients the sister was the key relative and for the remaining three cases the key relative ranged from cousin, son, to mother-in-law” (p. 197).

Gumber and Misra (2004) utilized the Five Minute Speech Sample (FMSS) and a self report measure to assess the coping strategies of the key relative being interviewed. This sample allowed them to identify the respondent’s attitude and feelings about the patient and also the quality of their relationship. When they interviewed the patient, they used the Self-report Quality of Life Measure for People with Schizophrenia (SQLS). This allowed them to assess the quality of life, psychosocial, motivation, energy, symptoms and side effects.

Forty-seven percent of the key relatives interviewed displayed a “negative relationship rating” (Gumber & Misra, 2004, p. 198). These negative responses were either due to several factors, including “the communication with the patients, lack of cooperation on the part of the patient and a lack of the patient’s ability to reciprocate, and withdrawal” (p. 198). The category with the highest percentage rating was that of

“critical comments.” Sixty-percent of relatives expressed criticism toward the patient in the following areas: *behavior resulting from illness*, including aggression, unpredictability, withdrawal, irresponsibility, noncompliance, anger, slowness, and the *patient’s failure to participate in gainful employment or lack of effectiveness in a work environment*. Overall personality-related behaviors included dependent behavior, lack of decision making ability, and regression. Emotional display was also assessed. Twenty-percent of family members cried during the interview. Their responses was due in part to past memories involving the patient, worries about the future of the patient, and/or distressed experienced by the relative caring for the patient. Gumber and Misra (2004) also discovered that 40% of the relatives displayed over-protective or self-sacrificing behaviors. Relatives were “taking extra steps and responsibilities to ensure patient’s well-being, health and development; letting the patient’s wishes and desires prevail at the cost of one’s own, protecting the patient from others or at the cost of other relationships, and the degree to which an attempt is made to engage the patient in fruitful employment” (p. 198).

Gumber & Misra (2004) concluded that the high levels of expressed emotion displayed by the interviewees indicated that their families were experiencing a considerable amount of stress. They inferred that high EE levels derived from the course and symptom expression of the illness and from the burden involved in caring for the patient. They suggested that future research should attempt to distinguish EE related to the illness and its burdens from EE related to interpersonal attitudes, phase of the illness, and specific patterns of impairment and disability.

The goal of a study conducted in Iran by Mottaghipour, Pourmand, Maleki, and Davidian (2001) was to determine the distribution of EE and its characteristics in affected families and to examine the predictive value of EE for explaining schizophrenic relapse in a sample of Iranian patients. The sample of 78 schizophrenic patients (age range was 16 to 60) came from two teaching hospitals -- one in Tehran (metropolitan area) and the other in Hamedan (urban area). The measurement tool used was the Camberwell Family Interview (CFI). Each subject lived with at least one key relative that was interviewed. Out of the 97 relatives interviewed, 45% were mothers, 27% were fathers, 20% were spouses, and 8% were siblings and children of the patients.

The results indicated that 60% of the patients resided within a high EE household. No significant differences were found for “type of family (extended-vs- nuclear), residence location (metropolitan-vs- urban), gender, marital status, and employment status” (p. 197). Level of emotional expression did not correlate with the family member’s relationship to the patient.

Only 47 subjects were available at the time of a nine-month follow-up. Thirteen patients had not recovered, 15 patients were lost to follow-up, one patient had checked out of the hospital without recovering, one patient abandoned the ward, and one patient committed suicide. Relapse rate in the high EE subjects was found to be 17 patients; in the low EE group, 9 had a relapse. The other 21 (9 in high EE and 12 in low EE households) did not have relapses. Mottaghipour, Pourmand, Maleki, and Davidian (2001) stressed the importance of community based education groups to help families cope with the illness of a loved one.

In Iran, following discharge from hospital, most patients must rely on family support with minimal community follow-up. Mental health services are based on a hospital oriented approach, with no community-care resources available. Therefore, the families' ability to cope with the illness becomes a critical issue (p. 197).

Families that have little or no community support could experience a higher rate of EE, and in turn, a higher rate of relapse.

Mottaghipour, Pourmand, Maleki, and Dividian's (2001) found that individuals suffering from schizophrenia exhibited higher rates of relapse if they were living in a high EE household. The researchers state that the high EE in these households could be the result of medication adherence, participation in follow-up programs, or differences in educational level

Thirty eight of the patients were illiterate or had little education and 62% had more than an elementary education.

Mueser, Bellack, Wade, Sayers, Tierney, and Haas (1993) examined the relation between the level of expressed emotion reported by family members and levels of social impairment displayed by the schizophrenic family member. They hypothesized that patients in families with members displaying high EE would be less socially skilled and less assertive than patients with low EE family members. They also hypothesized that patients with high EE relatives would be more impaired in their perceptions of negative affect than patients with low EE family members.

The study included a Role-Play Test (RPT), a Social Perception Test (SPT) and a Family Problem Solving Task (FPST) with the patient and relatives. The RPT assessed the patient's skill in managing interpersonal conflict; the SPT measured displays of "critical or benign expressions of emotion that were rated on dimensions of negative affect" (Mueser et al., 1993, p. 340), and the FPST measured the behaviors of family members during a discussion about a conflicting issue. Mueser et al. then conducted interviews with family members to measure the EE present in the family structure.

The subjects were 30 schizophrenia patients and 18 schizoaffective disorder patients (24 male and 6 female schizophrenia patients; 9 male and 9 female patients with schizoaffective disorder). All patients were receiving treatment at the Medical College of Eastern Pennsylvania Psychiatric Institute. The age range was 18-55 years. Subjects showed "recent symptom exacerbation or re-hospitalization, at least 4 hr/week contact with a member of the patient's family of origin and no evidence of organic brain syndrome, mental retardation, or recent alcohol or drug dependence" (Mueser et al., 1993, p. 341). Seventy-seven percent of the patients lived with one or both of their parents; they all provided informed consent and all were paid for their participation in the assessment. Sixty family members participated in the study--41 mothers, 16 fathers, 2 siblings, and 1 grandmother.

The family interview data were gathered using the Camberwell Family Interview (CFI). If the patient lived at home with both parents or had high contact with both parents, both were interviewed. If the patient did not live at home, the family member that had the highest amount of contact with the patient was interviewed. The interviews were audio-taped and later rated for criticism, EOI, and warmth using a Likert-type scale

format. Individuals rating the CFI were not aware of “the patient’s symptomology, social skill level, and family interaction ratings” (Mueser et al., 1993, p. 341).

The Role Play Test (RPT) for the patient was setup to acclimate the patient to the measure. This included two practice scenes to help them understand the RPT procedures. They then role played each of six situations twice.

The basic procedure entailed describing an interpersonal problem to the patient and then having the patient enact the situation with a research assistant who portrayed the patient’s mother, friend or roommate. The interaction extended through three verbal exchanges for each person, lasting an average of 22 minutes per role play. Six situations were empirically identified as reflecting common sources of conflict or disagreement in this population and as presenting moderate difficulty (e.g., the patient oversleeps and is late for an appointment). Responses of the confederate were scripted for each situation to reflect high criticism (based on criteria for rating the CFI, e.g., “You’re the laziest person I know!”) or benign expressions of disappointment or mild empathy (e.g., “You must have been really tired”) (Mueser et al., 1993, p. 342).

The Role Play Test was scored for four affective dimensions on a 5-point Likert-type scale: friendly-hostile, pleased-displeased, calm-angry, and understanding-critical.

The Social Perception Test (SPT)

consisted of a video-tape portraying 12 dyadic interactions that paralleled interactions on the RPT. A written description of an interpersonal problem was first shown on the screen and narrated by an off-screen voice. A female research staff member enacting the mother or roommate/friend role then appeared on the screen and engaged in a brief conversation with an individual in the subject role who was heard but not seen. As in the RPT, the mother or friend exhibited highly critical or benign disagreement (Mueser et al., 1993, p. 342).

After the exchange was completed, the patient rated the mother or friend on a series of “5-point semantic differential scales: pleasant-unpleasant, passive-intense, friendly-unfriendly, pleased-displeased, calm-angry, and understanding-critical” (p. 342).

The final test was the Family Problem-Solving task (FPST). This included areas of conflict between the patient and the family member with whom the patient had spent the most time. They divided the test into three segments--a warm up exercise and two 10-minute discussions dealing with problem issues.

After the warm-up exercise researchers video-taped and later rated data from the following scenarios:

After giving the instructions, the research assistant left the room for 10 minutes while the family completed the exercise. After the warm-up exercise the research assistant selected one problem area that had been identified in the

preliminary interviews, instructed the dyad to discuss this disagreement for 10 minutes, and then left the room again. After this discussion the research assistant identified a second area of disagreement, provided the same instructions, and left the room for another 10 minutes (Mueser et al. 1993, p. 342).

Mueser et al. (1993) rated the different domains on a 5-point Likert-type scale after each 10 minute interaction. These domains included: Quality of communication (overall effectiveness of the speaker, reflecting their believability, impressiveness, or presence); quality of problem solving (ability to remain focused on the conflict, openness to other's opinions); gaze (eye contact); utterance length; negative valence (the degree of negative feelings, including verbal and non-verbal); speech duration (amount of time the speaker talked); and dominance (the control or power the patient or relative had over the conversation).

The first hypothesis (patients with high EE family members would be less socially skilled and less assertive than patients with low EE family members) was measured at the conclusion of the RPT. Three multivariate analyses of variance (MANOVA) showed that “patients with low EE relatives were more assertive in response to negative than neutral affect from both family members and friends; whereas patients with high EE relatives were not more assertive with either. Furthermore, patients with highly critical relatives were significantly less assertive in response to negative affect from a family member than from a friend” (p. 344). They did find that patients with less disapproving relatives did not differ in their assertiveness with family members and friends. The MANOVAs on

the EOI and warmth measurements did not show a statistically significant difference on main effects (except for affect) or for interactions effects. Therefore, the social skill and assertiveness of patients in the RPT was not related to the family EE dimensions of EOI or warmth.

The second hypothesis involving the social perception test (patients with high EE relatives would be more impaired in their perceptions of negative affect than patients with low EE family members) was also measured using three MANOVAs. “For each MANOVA, affect (negative vs. neutral) was the within-subjects repeated measure, family EE (criticism, EOI, or warmth) was the between-subjects variable, and the affect ratings were the dependent variables” (Mueser et al., 1993, p. 345). The primary effect for affect for criticism, EOI, and warmth was significant, but no other main or interaction effects were significant. The six dimension-of-affect ratings were substantial, that is “the negative affect scenes were rated as more unpleasant, critical, angry, unfriendly, intense, and displeasing than were the neutral affect scenes” (p. 345). Therefore, patients that had relatives who were high in criticism, EOI, or warmth discriminated negative and neutral emotions as well as patients living with relatives who were low on these EE dimensions.

In summary, this study indicated that the warmth family members show toward the patient may be related to the patient’s behaviors and how they interact with family members. Patients that have highly critical relatives may not be able to effectively manage situations that are emotionally charged or are high in criticism.

Using secondary data analysis, Weisman, Lopez, Karno, and Jenkins (1993) conducted a study on Mexican-American families that had a member who suffered from schizophrenia. Two hypotheses derived from the attribution theory were tested. The first

hypothesis explored “whether attributions regarding the controllability of patient symptoms were related to EE status.” The second hypothesis tested evidence for a relationship between controllability attributions and affective reactions toward the patient.

The CFI test was utilized. The subjects consisted of 23 high EE relatives and 23 low EE relatives of schizophrenic patients. All family members were from public mental health service agencies in the Los Angeles and Ventura counties in California. Weisman et al., (1993), utilized the Index of Social Position, created by Hollingshead (1957); and discovered that almost all families were considered lower SES. All patients had been diagnosed with schizophrenia and were of Mexican descent. They were between the ages of 18-50 and were living with a spouse or other key relative prior to hospital admission. Fifty-seven percent were male.

In order for the families to be considered high EE, relatives had to have made at least six or more critical comments, expressed any degree of hostility, or scored 4 or higher (on a 5 point scale). Ratings of controllability and affect were made. Controllability was rated on a 5-point scale: 1 = no perceived control (the belief that the disorder and symptoms are God’s will and the patient can do nothing to change that); 5 = a great deal of control (the schizophrenic’s symptoms are a way of getting out of work, chores, or other tasks). “Guided by the attribution theory, affects were assigned to one of two domains: positive affects such as love, warmth, affection, sympathy, and sadness, and negative affects, such as frustration, annoyance, disgust, and hate” (Weisman et al., 1993, p. 603).

Results regarding the first hypothesis revealed that “high EE relatives would view the schizophrenic patient as having more control over the disorder and associated symptoms than would low EE relatives” (Weisman et al., 1993, p. 604). High EE relatives often blamed the patient’s symptomatic behavior on their refusal to comply with treatments and they also blamed the patient for acting out to get out of work or chores. The low EE families made “less controllable and less personal (rather than universal) attributions to their relative’s behavior than did high EE relatives designated by levels of criticism and hostility” (p. 605).

Results on behalf of the second hypothesis showed that sadness and annoyance were the most commonly reported affects in the high and low EE groups. The least reported affects were hatred and inability to tolerate. Also, “the types and range of affects expressed by high and low EE relatives overlap” (Weisman et al., 1993, p. 604). The most common expressed emotions in both groups were sadness, worry, annoyance, and frustration. “The critical difference in the expression of emotions between high and low EE groups appears to lie in the frequency with which negative emotions were expressed” (p. 604). Low EE family members were shown to have low frequency levels of negative affective responses. “Hence, negative affect appears to be the salient characteristic distinguishing high and low EE homes” (p. 604).

Weisman et al., (1993) noted the major limitations of their study. First, the findings are not “generalizable to high EE families identified on the basis of emotional over-involvement, despite past findings that high EE ratings on these are also associated with elevated patient relapse” (p. 606). Second, it is unclear if the perceptions of

controllability are causes or consequences of the relatives' emotions toward the patients. Potential cultural factors that may affect or mediate these relationships remain unknown.

Hall and Docherty (2000) examined the coping styles of parents dealing with offspring who suffer from schizophrenia and the predictors of expressed emotion. They sought to clarify how coping style relates to EE. In addition to assessing EE, they utilized the Strategic Approach to Coping Scale (SACS) created by Hobfoll, Dunahoo, and Monnier, 1993, to measure assertive action (whether a proactive approach was used when resolving the problem creating stress), social joining (interaction with others used to deal with problems), seeking social support (getting advice from friends or family members to deal with problem), cautious action (degree of careful assessment before acting to resolve the problem), instinctive action (following own instincts and personal strengths when resolving a stressful situation), antisocial action (attempts to deal with a problem that is creating stress by asserting dominance over others), aggressive action (utilizing aggression to deal with a problem), avoidance coping (passively dealing with stressors), indirect action (controlling events through the actions of others). Alpha coefficients in the scale range from .64 to .86.

The sample consisted of 44 parents and 24 patients (92% were male). All of the participants had been involved in a larger study of families of individuals with schizophrenia conducted by Docherty, Gordinier, Hall, and Cutting 1999. They utilized the CFI and the Scale for Assessment of Positive Symptoms (SAPS) created by Andreasen 1982, which measures aggressive behavior. Hall and Docherty (2000) conducted several sets of preliminary analyses. T-tests were utilized to compare mothers and fathers on their coping strategies and EE levels; t-test analyses were also conducted

to determine whether reliable differences existed between high and low EE parents on their coping styles. Third, co-relational analyses were run to assess possible relationships between the coping scale scores and levels of EOI and criticism. Several two-way ANOVAs were conducted to assess whether parental coping styles were related to patient aggression and whether these coping styles predicted levels of criticism in the mothers and fathers.

Preliminary analyses showed no statistically reliable differences between the mothers and fathers in their coping strategies or level of criticisms. The EOI scores were higher in the mothers than in the fathers.

The researchers also found that parents who were more assertive were less critical of their offspring; this suggests that these parents may be coping with their children in a more constructive manner. Parents who were assertive and made critical comments had children who were more aggressive. The researchers suggested that the critical comments by parents directed toward the offspring was prompted by the child's unacceptable behavior.

Yang, Phillips, Licht, and Hooley (2004) studied a sample of Chinese families to assess the effect of expressed emotion on patient relapse. Fifty-four individuals with an average age of 45.2 years participated in this study. This included 15 fathers, 9 mothers, 15 husbands, 14 wives, and 1 sister. Fifty-two of the relatives lived with the patients and the average amount of time spent together during the week was 34.5 hours. Out of the 54 patients, 29 were male with an average age of 31.1 and 25 were female, with no average age provided.

They predicted that:

1. Chinese relatives of schizophrenic patients would display a more situational (external, uncontrollable, and universal) attributional style than would relatives in studies in Western samples.
2. Despite this predicted overall situational bias of the Chinese relatives, highly critical or hostile relatives would have a higher overall rate of attributions and would make more internal, controllable, and personal attributions concerning patients' behavior than would low-EE and high-EOI relatives.
3. Schizophrenia patients whose relatives had a greater tendency to make internal, controllable, and personal attributions would be more likely to relapse during the 18 months after hospital discharge.
4. They further predicted that relatives' attribution style would no longer predict relapse once EE is controlled.

An audiotaped CFI was utilized to gather the data in this study. The patients' key relatives were chosen to participate in a semi-structured interview to assess their attitudes toward the patient. Three scales in the CFI were utilized: criticism, hostility, and EOI. They rated incidents that had occurred over the past three months, and discussed patient symptoms and the families' coping responses. Families were considered to be high EE if they were rated as having high hostility and/or high criticism.

The Leeds Attributional Coding System (LACS) was used to select attributions reflected in spontaneous speech. "In this study, the rater extracted (from the relatives'

CFIs) and then transcribed explanations given by relatives for negative events in the patients' lives (e.g., illness exacerbation, negative past situations or personal traits)" (Yang et al., 2004, p. 594). Each selected attribution was coded (0 or 1) on three different scales: Internal/external causal locus (the cause is believed to be inside or outside of the patient); personal/universal (personal refers the attribution indicating something negative about the patient and universal refers to the attribution as being caused by a reference group that the patient belongs to controllable/uncontrollable (refers to the patient and whether or not they have control over their circumstances).

Yang, Phillips, Licht, and Hooley (2004) found that relatives who believed that patients had control over their negative behavior rated high on criticism and hostility (high EE). These same relatives also believed that the patient's problems were personal and idiosyncratic to the patient. On the other hand, relatives who believed the problems that the patient was facing were uncontrollable rated high on EOI (low EE).

The link between patient and respondent characteristics and attributions was also examined. The goal was to "identify potential patient or family characteristics that might explain the differences found in attributional style among EE groups" (Yang et al., 2004, p. 597). The study found that the more education that the family had (patient and key relative), the less likely the relatives were to allude to causes that were internal to the patient. Patients that had lower functioning were thought to have causes that were internal. Male patients had a higher proportion of relatives who thought the causes were controllable and the males' relatives made more attributions per minute if the patient had been having an increased number of hospitalizations.

Attributions, EE, and psychiatric relapse were reviewed for 52 of the 54 patients. Twenty-four (45.2%) relapsed. The patients that had higher EE relatives tended to relapse more frequently.

Summary. Studies conducted on expressed emotion have been measurement oriented, thus aiding the validity and reliability of variables studied. These studies have been useful in understanding the stress levels, negative emotions, and quality of relationships that exist between primary caregivers and the schizophrenic family member in their care. Few studies focused on other adult family members and none dealt with the impact of this domain on children in the families. Theory was largely absent from these studies. Most studies omitted an analysis of the impact of education on the level of expressed emotion in families. Overall researchers found that the presence of high expressed emotion may lead the patient to have additional relapses. Each of the studies was correlational in design, making it difficult to discern causal cycles or dynamics of reciprocal effects between family members.

Burden on the Family

Families of individuals suffering from schizophrenia are often faced with many challenges, including feelings of helplessness, anger, despair, and anxiety” (Martens & Addington, 2001). “All studies to date agree that family members experience family burden, (but) there has been little agreement as to which factors influence the family burden (Lowyck, DeHert, Peeters, Wampers, Gilis, & Peuskens, 2004, p. 395). As with EE, researchers rely on key relatives to gather information and to assess the effects that the illness has had on the family. Research on burden has most often focused on objective and subjective sense of burden. “Objective burden involves the disruption to

the family/household due to the individual's illness, and is usually observable (i.e., household routines, relationships, and finances). Subjective burden involves the psychological consequences of the individual's illness for the family (i.e., health problems and distress)" (Martens & Addington, 2001, p. 128).

Perlick et al., (2006) conducted a study on components and correlates of family burden in schizophrenia. They utilized baseline data from the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study. This study was a "major multisite trial of antipsychotic pharmacotherapy funded by the National Institute of Mental Health" (Perlick et al., 2006 p. 1118). The study was conducted from 2001 to 2003 and utilized 623 family members. (The gender and relationship of family members to the patients was not specified.) These researchers hypothesized that caregivers would experience less burden from patients who had "lower symptom levels, a higher quality of life, superior cognitive functioning, fewer medication side effects, positive attitude toward medication, more years in treatment, and less intensive current treatment" (p. 1118).

The Positive and Negative Syndrome Scale (PANSS) was used to measure the symptom levels of patients. Quality of life was measured using the Heinrichs-Carpenter Quality of Life Scale, and cognitive functioning was assessed using the neurocognitive assessment scale. Three tests were utilized to measure medication side effects. The Family Experience Interview Schedule (FEIS) was used to measure the sense of burden of family members.

Four burden factors were targeted: problem behavior, resource demands and routine disruption, impairment in activities of daily living, and perceived patient helpfulness. After demographic characteristics (e.g., age of caregiver, years of illness,

finances), symptom level was the strongest predictor of burden across all four measures. “The four burden factors were differentially related to the PANSS negative and positive symptoms dimensions. The problem behavior factor was significantly and positively associated with positive, but not negative, symptoms whereas the reverse was true for impairment in activities of daily living, which was positively associated with negative but not positive symptoms” (Perlick et al., 2006, p. 1120). Disruption of routine was positively and significantly related to both positive and negative symptoms. On the other hand, perceptions of patient helpfulness was not related to the positive or negative symptoms.

Key relatives tolerated more inconveniences if they felt that the patient was doing his/her share of the work in daily life (e.g., chores, working); but even when the florid symptoms were under control, family members were still concerned about the patient’s ability to attain a normal social life, employment, and recreational activities. The overall enjoyment of one’s life may possibly be related to specific facets of caregiver strain.

The patients’ use of and attitudes toward mental health services contributed to the perceived burden of family members. Inpatient service use was related to increased sense of burden after controlling for patient symptom level. The researchers noted that “additional information is needed to understand these relationships (i.e., clarification to family members on how patient services might best relieve family burden) and under what circumstances it might exacerbate perceived burden” (Perlick et al., 2006, p. 1123).

Cognitive functioning did not play a role in level of burden. However, because they “investigated only cross-sectional associations of neurocognition with burden, our

findings do not preclude the possibility that neurocognition may affect caregiver burden over a longer observation period” (Perlick et al., 2006, p. 1123).

The demographic characteristics of the patient and caregiver did relate to three out of four sense of burden factors. Younger patients who were residing with the key relative inflicted more burden on their families. The researchers note, however, that as younger patients get older they tend to have a higher rate of recovery and become less dependent on their family. They advise that it is important to keep in mind that the demand on resources and disruption of routines has to be balanced out with the participation (chores, working outside the home, etc) that they feel the patient is contributing.

As the authors acknowledge, though this was a large study, a few caveats need to be attached to the findings. First, only about half of the 1,460 patients family members in the CATIE study, participated; so it cannot be concluded that all families with a relative suffering from schizophrenia would respond the same way. Second, this was a clinical trial sample so it may not represent individuals in treatment or others suffering from schizophrenia. Finally, the cross-sectional design does not afford causal inference regarding relations among the factors studied.

As to practice implications, Perlick et al. (2006) recommend that family interventions might focus on expanding training to patients and key relatives about wellness recovery, skills training, and task sharing of household and self-care chores. Improvements in these areas “are most likely to meet the needs and enhance the quality of life of people with mental illness and their families” (Perlick et al., 2006, p. 1124).

In Arica, Chile, Caqueo-Urizar and Gutierrez-Maldonado (2005) researched burden of care in families of patients with schizophrenia. Their sample was comprised

of 41 caregivers (26 mothers, 6 fathers, 4 siblings, 1 child, 2 spouses and 2 mental health staff), all of whom attended Mental Health Outpatient Centers. Thirty-three of the family members had not completed secondary school and 23 were not in paid employment. Of the 41 patients, 26 were men, with a mean age of 33.3 years. Thirty-seven of the patients were unemployed, but only 17 were receiving government assistance.

The self-administered Zarit Caregiver Burden Scale was used to complete the assessment. This measurement tool has three burden subscales: subjective impact due to care, feelings of rejection or hostility toward patient, and self-evaluation of competence in handling care. The 22 items on the Zarit Caregiver Burden Scale explore negative effects on the caregiver in relation to physical and mental health, social activities, and economic resources. The total score may range from 22 (no burden) to 110 (intense burden). Questions included on this scale were: “Do you feel that your relative asks for more help than he/she needs?”; “Do you feel embarrassed over your relative’s behavior?”; “Do you feel angry when you are around your relative?” “Do you feel you should be doing more for your relative?” (Caqueo-Urizar, & Gutierrez-Maldonado, 2005, p. 721).

Results show that key relatives who were older, unemployed, less educated, and who were caring for a younger patient had higher levels of burden. “Coinciding also with previous research, mothers show the highest level of burden because they usually are the key carer” (Caqueo-Urizar, & Gutierrez-Maldonado, 2005, p. 722).

“The educational level is a variable that can modulate the degree of burden experienced by the relatives. In previous studies, it has been found, as in this research, that the carers with higher levels of education have less burden” (p. 723). Those key

relatives with higher levels of education have a greater knowledge of the disorder and of resources available to them and their family member. In order to benefit from economic and mental health resources, families with lower levels of education need to be educated in these areas.

According to Magana, Garcia, Hernandez, and Cortez (2007), three quarters of Latinos who suffer from schizophrenia live with a family member. Psychological distress among U.S. Latino family caregivers of adults with schizophrenia was the focus of a study done by Magana, Garcia, Hernandez and Cortez (2007). They interviewed 85 Latinos that were caring for an adult suffering from schizophrenia (50 mothers, 14 spouses, 12 siblings, 5 fathers, 4 were other relatives). The average age was 55 years, the majority was female and almost half were married and had less than nine years of education. All were recruited from mental health facilities or out-patient programs. Forty-five caregivers came from El Paso, Texas, 13 came from Milwaukee, Wisconsin and 27 were from Los Angeles, California.

Assessment of family members was accomplished by using the Zarit Burden Scale, with each question being answered on a three-point scale (0-not true at all and 2-extremely true). Stigma was assessed using a 5-point scale (1-never to 5-always); Cronbach's alpha was .84. "These items asked about the extent to which family members avoided having family and friends over or avoided telling other about their child's illness for fear of what others may think of them" (Magana et al. 2007, p. 380). Depressive symptoms were measured by using the Center for Epidemiologic Studies-Depression (CES-D) scale. Depressive symptoms that had occurred over the past week were rated on a scale of 0-rarely to 3-mostly or all of the time; Cronbach's alpha was .90. "Caregivers

depressive symptoms correlated with caregivers' younger age, lower levels of education, and higher levels of burden and stigma. Patients' male gender and psychiatric symptoms were also related to caregivers' depressive symptoms" (Magana et al. 2007, p. 380).

Magana et al., (2007) used a stress-process model to examine the relation of the patient's psychiatric symptoms and the caregivers' depressive symptoms. After adjusting for demographic variables (e.g., caregiver's age, gender, marital status, and education) they discovered that psychiatric symptoms (patients' positive psychiatric symptoms), stigma, and burden were all closely related to depressive symptoms suffered by key relatives.

"Mental health of Latino family caregivers is an important focus for research and intervention-- 40% of caregivers in the study presented here met the criterion for being at risk of depression (that is a score of 16 or higher on the CES-D scale)" (Magana et al. 2007, p. 382). It was also established that the more positive symptoms that patients' have, the greater feelings of burden among the caregivers, which in turn is related to depressive symptoms.

Independent of other variables, stigma was closely related to caregivers' depressive symptoms (Magana et al. 2007, p. 382). More research needs to be conducted in this area to determine if negative symptoms have an impact on the relationship between psychiatric symptoms and stigma. This study focused solely on positive symptoms. "Negative symptoms may appear to family members as laziness, or behaviors that can be controlled by the patient which may be more stigmatizing to families" (Magana et al. 2007, p. 382).

The researchers recommend that in addition to focusing on the symptoms of patients, more attention needs to be given to the mental health and well-being of family caregivers. Lowyck, DeHert, Peeters, Wampers, Gilis, and Peuskens (2004) studied family burden among 150 family members of schizophrenic patients. The first purpose was to gain more insight into the extent of family burden (FB) experienced by family members of schizophrenic patients. The second was to gain a better understanding of the factors that influence the family burden.

All key relatives (46 male and 104 female) who participated were either the parent or partner of the patient. Patients included 103 males and 47 females, with an average age of 33, and each was receiving in- or out-patient treatment at one of two hospitals in Belgium. The Interview for Family Burden (IFB) was the measurement tool. This tool measures socio-demographic data of the patient and family member, symptomatic behavior (depressive and anxious symptomatic behavior, disorganized symptomatic behavior and negative symptomatic behavior). Using a 4-point scale, burden variables can also be measured using the IFB; these include (p. 397):

1. Practical/domestic tasks; efforts on behalf of patient, exchanging tasks, extra work.
2. Atmosphere in house, tense atmosphere.
3. Emotional consequences; emotional burden and the concerns of the respondent for the other family members.

The emotional burden scale consists of the sum of the following scales (concerns for the patient and for oneself,

the extent of the inconvenience, and the extent to which one felt burdened).

4. Major incidents: inconvenience for family member, break in contact with family/acquaintances

5. Financial contribution of the family for the patient in the past year.

The main statistical methods used were the analysis of variance (ANOVA) and the Pearson correlation coefficient.

Lowyck et al. (2004) found that parents and partners of the patient became more involved on an emotional and practical level once the individual became ill. An additional burden for caregivers was for those patients that had been treated for less than a year; key relatives not only worried about the patient, but also about the other family members. Parents had taken over more tasks and contributed more financially than did the partners. Due to this additional burden, parents reported more stress at home than did partners. Lowyck et al. (2004) attributed this to the fact that parents are usually the caregivers when the illness begins.

The main correlate of family burden researched in this study was the symptomatic behavior of the patient. The researchers found that the more symptoms that the patient displayed, the higher the family burden. This study did not find a difference between positive or negative symptoms and the effects these had on the caregiver. Lowyck et al. (2004) attribute this to the measurement process, where the family member is asked about patient symptoms. They also state that if “when symptoms are rated by a mental health

professional, a better and more precise differentiation between the symptoms is obtained” (p. 401).

Lowyck et al. (2004) conclude that key relatives taking care of the patient do experience an ample amount of burden, on both a practical and emotional level; also, they conclude that number of the symptoms exhibited by the patient was an influence on family burden.

In an attempt to understand the experiences that family members go through when caring for an individual with schizophrenia, Martens and Addington (2001) researched “whether a measure of caregiving would be a stronger predictor of the psychological well-being of families who have a member with schizophrenia than a measure of burden” (p. 129).

Martens and Addington (2001) selected a sample of 41 family members (23 mothers, 10 fathers, 4 siblings and 4 spouses) of 30 individuals (20 male and 10 female) suffering from schizophrenia and schizoaffective disorder. The 30 patients had a mean age of 29.6 years, were participating in an outpatient program in Calgary, and had an average length of illness of 6.0 years.

The measures utilized for this study were the Psychological General Well-being Schedule (PGWS), which has 24 questions with answers ranging from 0 to 5 (0=everyday, all of the time to 5=none of the time, not at all). When answering the questions, respondents were asked to rate how they had felt regarding the target of each question within the past month.

The Experience of Caregiving Inventory (ECI) was also used to assess how much the caregiver thinks about the impact or consequences of the illness. This self-report

measure has 10 subscales: eight negative (difficult behaviors, negative symptoms, stigma, problems with services, effects on the family and the need to provide backup; dependency and loss) and two positive (rewarding personal experiences and good aspects of the relationship). The ECI asks various questions (i.e., during the past month how often have you felt...or how often have you thought about...). These questions are rated on a scale of 0 (never) to 4 (nearly always). The Family Concern Questionnaire (FCQ), a subjective, self-report measure as also used. It consists of 46 questions assessing the degree of burden experienced by the target family member. The answers are measured on a scale of 1 (has not been a concern) to 5 (always a concern). Examples of questions include: “Has your relative caused any trouble with the police?” or “Has your relatives’ illness made it difficult to plan for the future?” (Martens & Addington, 2001, p. 130).

The researchers found an overlap between the reports gathered from the Family Concern Questionnaire and the negative scale of the Experience of Caregiving Inventory. They felt that “the negative scale of the ECI was the best predictor of poor psychological well-being. However, scores on the ECI positive scale were not associated with psychological well being” (Martens & Addington, 2001, p. 131). A closer look at the ECI subscales showed that psychological well-being was related to issues about stigma, problems with family, dependency, loss and difficult behaviors.

Though it was not a statistically significant predictor in the regression analysis, length of the illness accounted for 9% of the variance in psychological well being; higher distress was found among family members who experienced their first onset of schizophrenia. However, burden was not more severe for those whose relatives had been ill for a long period of time.

The limitations to this study include the small sample and the fact that it was comprised of volunteers (which could indicate that the family may be more stable). “As a result, the within-family variance and the between-family variance is blended together. Thus there is the risk that the responses of caregivers may be more highly correlated within families than across families” (Martens & Addington, 2001, p. 132).

Martens and Addington (2001) concluded that the measure of caregiving was a stronger predictor of the psychological well-being of families who have a member with schizophrenia than was the measure of burden, particularly in family members of individuals experiencing their first episode of schizophrenia. They urge more research in two areas (p. 132):

First, there is a need for more qualitative in-depth details about what is involved in both positive and negative aspects of caregiving and the difference in coping styles between family members. Secondly, the changes families go through over time in response to the impact of having a relative with schizophrenia need to be addressed. Such a longitudinal study would lead to a more comprehensive understanding of how the coping and response styles of a family change over time, from their relative’s first onset to periods of recovery and through possible relapses.

Some family members who care for those suffering from schizophrenia may feel a sense of satisfaction or gratification; others may feel that the burden of caring for their loved one has disrupted most aspects of their life (work, leisure, social). Baronet (2003)

assessed the impact of family relations on caregivers' positive and negative appraisal of their caretaking activities. Ninety- seven family members from Edmonton, Alberta, Canada voluntarily participated. All key relatives were either a parent (69%) or spouse (31%) of the patient, and were recruited through psycho-educational and support groups. Seventy-percent of participants were women and 96% were Caucasian; the average age was 54.

The Burden Assessment Scale (BAS) measured embarrassment, feeling guilty that they had not done enough or caused the relatives illness, stigma, resentment, worries about their future, and things getting worse. The 6-item self-report Care Work Satisfaction Scale created by Orbell, Hopkins, and Gillies (1993) was administered to measure the satisfaction family members derived from providing care. Questions included: "Caring for (name) makes me feel good about myself," and "I find my caring activities rewarding and fulfilling" (p. 139).

Baronet (2003) also utilized the McMaster Family Assessment Device (FAD), a self report measure of the quality of the relationship between the key relative and the patient. Two of the 12-item, subscale examples are: "Planning activities with (name) is difficult because we misunderstand each other" and "(Name) and I don't get along well with each other" (p. 140). The family member then uses a 4-point scale (1=strongly disagree to 4=strongly agree) to rate their answers. The alpha coefficient of the subscale was .87 (p. 140).

The moral and emotional support offered by family members, other than the patient was measured by using the Procidano and Heller (1983) Perceived Social Support from Family scale (PSS-Fa). Another self report, the 20 items are answered with yes (1)

or no (0). Families who score higher on this measure, feel that they have a high level of support from family members. The alpha was .92.

Baronet's (2003) hypothesis supported the fact that relationship difficulties between the key relative and patient were related to higher subjective burden and low satisfaction of caregiving activities. On the other hand, family support was not associated with either subjective burden or satisfaction received from caregiving activities. Family support was included in this study because it was assumed that given the large amount of time that caregiving takes, the caregiver may be isolated from social contacts and activities and, thus, family support may become more important. The participants sought support from other social outlets; this may mean that they did not perceive the support offered by members adequate in fulfilling their needs and in lessening the feelings of burden.

The limitations in this study included: "a) the limited generalizability of the study findings; b) the response rate of study participants, c) the small sample size and the issue of shared methods of variance in the measurement of objective and subjective burden" (Baronet, 2003, p. 142). Two other aspects are noteworthy. This group of participants was drafted from support and psycho-education groups and, thus, may have a better understanding about the illness than those who are not in such groups.

How well do demographic characteristics, social and family factors, and health conditions predict the level of perceived burden of the Chinese families caring for a relative suffering from schizophrenia? This question was targeted by Chien, Chan, and Morrissey (2007).

Their cross-sectional descriptive study, recruited a random sample of 203 key relatives (91 male and 112 female; 59 children, 64 parents, 41 spouses, 39 siblings/others) from three regional psychiatric outpatient clinics in Hong Kong. Family members were asked to complete a set of four well-validated questionnaires. These included the 25-item, semi-structured Family Burden Interview Schedule (FBIS) developed by Pai and Kapur (1981); the 60-item Family Assessment Device (FAD) developed by Epstein, Baldwin, and Bishop (1983), assessing several dimensions of family functioning; the Sarason, Sarason, Shearin, and Pierce (1987), Six-item Social Support Questionnaire (SSQ6) that determines the number of supporting persons that each key relative has, plus their satisfaction with that support; and the Ware, Snow, Kosinski, and Gandek (1993) MOS 36-Item Short Form Health Survey, with eight subscale items assessing bodily pain, physical problems, vitality, social functioning, mental health, social functioning, and emotional problems.

The overall score for the FBIS and its six domains of caregiver burden were found to be high. The findings of this study reinforced the findings of a study conducted by Pearson and Lam (2000). Many Chinese families are unified and depend on each other for emotional and social support in daily life. They stress interdependence instead of independence and are “very anxious and persistent in providing physical and psychological care to their relative with severe mental illness and ensuring that the relative receives the best possible care” (McCubbin and McCubbin 1993, p. 1158). These factors mixed with socio-demographic factors may increase the risk or vulnerability “for perceiving burden and the resulting distress and negative consequences

such as guilt, self -blaming, social isolation, depression and even self-harm or suicide” (Chou, 2000, p. 1158).

Two other factors resulted in higher burden levels--age of key relatives and economic status. In traditional Chinese culture, the elders are head of the household; so the physical and psychological strain of caring for someone with schizophrenia may put additional stress on an elder who is already suffering from his or her own health issues. The economic status could have resulted from unemployment, the larger number of family members living in the household, or unfavorable living conditions.

Limitations of this study include: a limited random sample selected from just one area of Hong Kong; exclusion of patients who have had schizophrenia longer than five years; selection bias resulting from the all-volunteer sample; and only one primary caregiver for each patient participated in the study.

However, this study helped to identify important cultural aspects regarding how the Chinese may handle relatives or loved ones suffering from a mental illness. “This understanding also helps health professionals and researchers to identify different sources and domains of burden from a Chinese cultural perspective and take into account of these factors when planning interventions for family caregivers” (Chien et al., 2007, p. 1160). Researchers need to continue to take into account the cultural differences in independence, literacy, health behaviors and attitudes, and living conditions with extended family members when working with different populations.

Summary. As with research on expressed emotion, the research on burden of care has been largely correlational in design and has targeted primary caregivers. No study included children as a target of study. Also, family dynamics has not a target of study.

Another area that may have an impact on the research of burden of care is culture.

Researchers may find that objective and subjective burden of care may vary as a result of direct as well as moderating impacts of cultural factors affecting family dynamics.

Finally, as with expressed emotion, theories were not applied to burden of care research.

Developmental and family systems theories may also help us to understand how the illness can affect every aspect of a person's life. Also, longitudinal designs may shed some light on the burden children may experience as they grow older and have to take on additional burdens when caring for a schizophrenic parent.

CHAPTER THREE

A Personal Story

On July 21, 1970 in Kansas, I was born into a family that consisted of a father, mother, and two sisters. When I was one year old, my parents divorced and my two sisters and I lived with our mother. During my early childhood years, my mom was a college student and worked fulltime to support our family. We had a babysitter to watch us in the evening and two of my aunts would help care for me while my sisters were in school. Our dad worked out of state, so we would see him about once a month. When I was in third grade my mom remarried and I believe she felt like she was finally giving us a “normal” family.

In the spring of 1982, schizophrenia touched our family. I was 11 years old and in fifth grade. My mother, who was 35 years old, had her first psychotic episode. I believe that I have blocked out the days leading up to her first hospitalization, because the only thing I remember about that time was the night before she went into the hospital. My bedroom was in the basement of the townhouse that we lived in, and there was a half bath right above my bedroom. I remember waking up in the middle of the night to hear my mom and step-dad arguing in that bathroom. She was having delusions, talking to herself, playing very loud music and then they started screaming at each other. I grabbed an empty Pepsi bottle that I had in my room and held it in my hands. I kept thinking that if my step-dad started to hurt her, I was going to protect her and run up the stairs and hit him with that bottle. I was so scared listening to what was going on; I do not even remember if I ever fell asleep that night. I do know that the next day there was a family meeting with my step-dad, middle sister, aunts, uncles, and grandparents to discuss

mom's "bizarre" behavior and what should be done to find help for her. A family friend recommended that we take her to the hospital in Halstead, Kansas.

After mom was admitted to the hospital, it was explained to me that she had a "nervous breakdown" and that she would be in the hospital for a few weeks. I did not understand what a "nervous breakdown" was, just that she had too much stress in her life and it became too much for her to handle. During those few weeks, my middle sister and step-dad took care of me and took me to visit my mom a couple of times. When she came home it seemed to be such a happy time. She was stable and on medication (lithium), went back to work as a drug and alcohol counselor, and life went back to normal. She told all of us that she would not have to go back into the hospital again and that she was much better.

That first hospitalization was just one of the many dozens that our family endured over a period of 19 years. The next episode happened at the end of my sixth grade year. My mom started having delusional thoughts again, the family came together to take her back to the hospital in Halstead. This hospitalization was the first, but not the last time she would miss a milestone in my life. During this particular hospitalization, she missed my sixth grade graduation. I was fortunate enough to have the rest of my family there for support, but I had mixed feelings. I was sad because my mom was not there, but, on the other hand, I was glad that she was not because her behavior would have been embarrassing to me. Like the previous times, she came home stable, on medication and went back to work and life was back to normal; and once again she told us that she would not have to go back into the hospital. At this point I still believed her; that it would not happen again.

The next hospitalization that I remember occurred when I was in seventh grade. By this time my mom and step-dad had divorced (although he continued to come around on a regular basis). My middle sister was graduating from high school and moving out of the house; my oldest sister, had already been out of the house for a few years. This time it was Easter that my mom missed. Holidays were always such a big celebration in our family and even though I did not believe in the Easter Bunny anymore, I was sad because my mom would not be home to fill my basket up with goodies. My middle sister made sure that I had an Easter basket that year and that we made it to the extended family Easter dinner. I do not remember the family really discussing mom being gone. I just remember that everyone was supportive and made sure we had a good Easter. I believe there was another hospitalization during my seventh grade year because I vaguely remember one of my aunts and uncle taking me in for a few weeks during this time period. I remember having a feeling of safety and security while staying with them. I knew I would not have to deal with my mom's illness, I would have a roof over my head, a comfortable bed to sleep in and food on the table every night; I could just be a kid.

Over the next four years (I was 13-17 years old), there were several more hospitalizations, too many for me to remember. During this period I started to hear the family refer to her illness as "bipolar." Until then I always just thought she had another "nervous breakdown." We were starting to get into a rhythm of what steps we were going to go through when she was headed down the path of another hospitalization. About three weeks prior to going to the hospital she would start to say things that were not in her character. We would count her pills, ask her if she was taking her medication. Then she would become very agitated with us and say "yes," she was taking her

medication; but we knew that was not true. Deep down inside I had always hoped that if she thought we were suspicious of her not taking her medication, she would start taking it again and she would not have to go back in the hospital; but that never happened. I would start to feel scared inside and have a lot of anxiety because her behavior was unpredictable, and I would start to wonder what this psychotic episode was going to bring. I would stop having friends over in this three-week period, because I never knew what she was going to say. In the two weeks prior she would start to isolate herself from the people that she interacted with the most, but would call friends that she had not talked to in a long time. This would lead to a chain reaction of phone calls from her friends asking if our mother was doing okay. I always felt so embarrassed when these phone calls would start coming in. We would explain that she had stopped taking her medication and we were playing the waiting game and that it would probably be another week before we could get her to go to the hospital. The week prior to taking her to the hospital, the delusions would start and the things that she would say made no sense at all. For example, she would claim that Howard Hughes was her dad, that my sister had a different dad than her real one. She began staying up all night talking to herself, playing very loud music, watching the same movie over and over again and she would start doing bizarre things, like throwing away pictures, jewelry, bills, and would be spending so much money that checks would start to bounce. It was at this point that we knew we would be able to tell her a story (that we were going on a vacation or going shopping) to get her into the car and take her to the hospital. During this time we also began taking her to a hospital in Wichita and some of her friends that she worked with would also help us in getting her there.

My next vivid memory and milestone that mom missed was my junior prom. She had taken me to Wichita to buy my dress and shortly after that she was back in the hospital. Her bizarre behavior during the week prior to this hospitalization seemed to be worse with this episode. I did not understand why she kept choosing to stop taking her medication. It would make me so angry; could she not see what it was doing to her family and did she even care? She was starting to behave more aggressively--slamming the kitchen drawers, slamming knives down on the counter when she would want to cook something, and the worst of all, boiling her cigarette butts in oil on the stove. I had always felt a lot of anxiety in the weeks leading up to a hospitalization; but this was the first time that I really did not feel safe being in the same house with her. She wanted to come home for a visit over prom weekend, but I told my middle sister to talk to the hospital and let them know that I did not want her to come home for that visit. My friends were coming over before we went to dinner on prom night and the last thing that I wanted was for my unstable mother to be home. At this point in my life I was so ashamed of my family, so many people that I went to school with had no idea what my home life was like. The only people that ever really knew were a few very close friends and my boyfriend, whom I dated all through high school. I was able to confide in those close friends; but my boyfriend was really the only one who saw first hand what was going on in the house when she would stop taking her medication. He even became involved when it was time to take mom to the hospital. He would help us come up with a story to get her in the car and even went on a few trips to the hospital. I was getting to the point where I did not want to live with her anymore. One of my other aunts and uncle asked me if I wanted to come and live with them the last couple of months of my junior

year in high school. I did go live with them for a couple of months and it was good to have that safe and secure feeling again. Those were two things that I very rarely felt anymore when I was at home with my mom; but I knew that at some point I would have to go back home.

After living with my aunt and uncle for a few months, I moved in with my dad for the summer. I had stability at his house, but having lived my life with no structure and no rules I decided that I should go back and live with my mom; after all living with her meant that I would be able to do whatever I wanted. My senior year of high school brought a lot of rebellion. I felt like I had no respect for my mom; at this point in my life she had missed so much and I practically raised myself with some help from my middle sister, aunts, and uncles. Mom very rarely knew where I was, what I was doing, or whom I was with. I was just looking forward to getting out of school and transitioning into adulthood. I had no plans to go to college right out of high school and my attitude was that I had been through so much during my childhood I had this overconfident, “I know everything” attitude,” nobody can tell me anything that I do not already know”. During high school and after I graduated, I worked in a grocery store. It was not my ideal job, but I knew that is what I was going to do until I figured out just what it was I did want to do.

In 1990, when I was 19 years old, my high school boyfriend and I started living together and then we got engaged. Everyone seemed to be happy and excited for us and I felt like I was making the right choice; in the back of my mind I thought that my fiancé was the right person for me, and he was the one person who would not judge me for what I had gone through during my childhood; he loved me even knowing and seeing what I

had gone through. I was bound and determined to have a “normal” family. After I moved out of the house I felt like my relationship with my mom was improving, so I included her in the wedding plans and she even had an engagement party for us. In the month prior to my wedding, things started to unravel again and we knew that she was going to be back in the hospital within a couple of weeks. The next milestone in my life that my mother missed was the wedding. I do not remember being mad at her; just relieved that she was in the hospital before the wedding. I had always worked so hard at keeping people I knew away from the “situation” and I did not want to have to explain her behavior to anyone, on one of the happiest days of my life. I was so fortunate to have my family rally around me and support me on that most important day. My aunts made sure that the guests were aware of the situation and they were asked not to bring up my mom. They wanted the day to be special and not filled with a lot of questions and unnecessary anxiety for me. We were able to enjoy our day and go on our honeymoon. After we got back, mom was still in the hospital for another week or so. After she got out, she came to our house to bring us our wedding present. I remember having total disregard of her and obviously feeling hurt because she had missed one of the most important days of my life. It was at this point I knew that our relationship had changed drastically, and not for the better. During this time we tried to go to counseling as a family (mom, middle sister, and myself), but most of the sessions consisted of mom trying to convince us that she was doing so much better and that she would never have to go back into the hospital again. My middle sister and I would get so frustrated and did not want to go to anymore sessions because we knew that it would just be a matter of time and she would end up in the hospital.

After nine years of being mentally ill, mom started to lose relationships. The closeness she had with her sisters, parents, and even her kids, were fading. Most of her close friends stopped spending time with her and we also knew that she would probably not work in another professional job for the rest of her life. For many years she was able to be hospitalized, get stabilized, come back home and go back to a normal life; but that was not the case anymore. Over the next nine years we had more hospitalizations and her mental health, even when she was stabilized, seemed to be deteriorating. She seemed to be apathetic, tired, and responded a lot slower than before. During this time they had to take her off of the lithium that she had been on for so long because she was starting to have problems with her kidneys. During one of the hospitalizations, it was discovered that she had been misdiagnosed. The doctors explained to her that she was not bipolar. They re-diagnosed her with schizoaffective disorder (subtype of schizophrenia, same symptoms but with a mood disorder attached to it), anxiety disorder, and also obsessive-compulsive disorder.

Due to the changes in the laws, getting her to the hospital and having her committed was not as easy as it had been in the past. She had the right to turn around and walk out the door, just as soon as we had dropped her off. We also knew that she would never agree to admit herself to the hospital, and the doctors would not admit her involuntarily until we had a court order proving that she was a danger to herself or others. A new step that we had to start taking was waiting until we thought she was doing something that could harm herself or others. In a matter of 24 hours, once we felt like we had that proof (burning things or even driving her car). We would have the police or sheriff's department pick her up or we would try and get her to the hospital in Salina,

where they could keep her for 24 hours. She would then have to go in front of the judge so that he could deem her harmful to herself or others. Even though court order was more convenient for us as a family, because we were not responsible for getting her to a hospital anymore, it was a very emotional process to go through. Watching her have to go in front of the judge, listen to him deem her harmful to herself or others, and then see the sheriff's department handcuff her, load her and her suitcase in the van to go to Topeka or Larned State Hospital was one of the most difficult things I ever had to watch.

In the spring of 2001, our family hit a turning point that has changed all of our lives. Mom had stopped taking her medication again and we were headed down the path of getting her court ordered to the hospital again. I explained to my middle sister that I thought we should just let it go this time and let her suffer the consequences of not taking her medication. We had always been there to "bail" her out, almost like enabling her behavior. My middle sister and I worried about what those consequences would be; but we also knew that something had to change. We took away mom's checkbook and car keys and prayed for the best outcome. My middle sister was contacted by the police department. They told her that one of mom's neighbors had called the fire department because mom had been burning books on her barbeque grill. It was at that point that the police were called to take her into the police station. They realized how unstable she was and they took her to the hospital. We did not have to do anything at this point because the judge was aware of what happened and he ordered her to Larned. The aftermath of this hospitalization was the worst. Mom had not paid her rent, so in two days after her hospitalization our family and friends rallied around my sister and I to help us move mom out of her house. We rented a small storage space, moved what belongings were

salvageable, and took her bird to the dog pound. My aunt took her dog. We let her bills go unpaid. Her car was repossessed; then we waited for her to become stabilized so we could explain to her what had happened with this episode. When she realized that she was going to be homeless, not have a job, or any money, she decided to stay in the hospital a little longer and try to get some additional therapy. She finally realized that her family was not going to be there to help her out of this dilemma. My middle sister and I let her make all the necessary phone calls regarding her bills, her car, and her rent.

After mom got out of the hospital, she ended up living in a homeless shelter in Salina. She found a job and started working her way out of the mess she had gotten herself into. She eventually moved into a transition apartment that the homeless shelter owned, and they had given her a car that had been donated by somebody in the community. She then worked and saved enough money to rent another place to live. I can happily say that it is 2008 and she has not had any more hospitalizations. Losing everything she owned, living in a homeless shelter and having to work from the bottom up, helped her to realize the importance of taking her medication and taking care of her mental health; I think she also realized that her family was not going to be there to help her if she continued to make the decision not to take her medication.

Even though it has been seven years since the last hospitalization, the overall effect this has had on my life is very hard to put into words. So much of my childhood was filled with anxiety. I started suffering from migraines around the time she was first hospitalized, up to the time I moved out of the house at 19. I believe part of that was from the stress of wondering when the next hospitalization was going to occur, what her behavior would be like, how the rent and bills would get paid while she was gone. There

was always so much to take care of after she was hospitalized; people to call and explain why she could not come to work, why we could not pay the bills, why her checkbook was overdrawn and trying to find things that she had thrown away or torn up (jewelry, bills, pictures, etc).

As a child and even through my teen years, I always thought that if I did things to help out while she was gone and after she got home, she would not have to go back into the hospital again. I would clean the house from top to bottom, make sure all the laundry was done and run errands. I was usually happy when she would come back home and just as most children you want to believe your parents when they tell you something; so for the longest time I really believed her every time she would say that she would not be hospitalized again. Looking back now, I think of her as the boy who cried wolf.

Over the last seven years my mom has been able to hold down a steady job, and just recently got off of disability and is able to work full time again. When I think about her life and what it must be like, it makes me so sad. She has a college education, is very intelligent, would help anyone who would ask and always seemed to have the world by the tail. I remember family members and her friends would always come to her for advice; they stayed close to her even know that because of the illness I keep her at a distance as a way of protecting myself from being emotionally hurt again. I hope now that I have a better understanding of schizophrenia and the effect it has had on many families, we can start the healing process and maybe be close again someday.

CHAPTER FOUR

Conclusion

As the research review indicates, empirical research on the impact of schizophrenia on families has been relatively active, particularly over the past 15 years. Research on expressed emotion began somewhat earlier – in the early 1990’s -- than studies focusing more specifically on burden of care – more prevalent in the past ten years. Expressed emotion has been used to infer quality and style of relations among family members, as a predictor and “proxy” of stress level within families, as a predictor of coping strategies and illness attributions, and, at times, as a predictor of patient outcomes such as institutionalization. Burden of care studies have focused largely on subjective sense of burden reported by primary caregivers, its possible mediating and causal roles for quality of life outcomes for caregivers and families, and have been used to assess the unmet needs of key caregivers. It should be stressed that almost all of the existing research is correlational in design – that is, all of the data information are gathered at the same point in time. Thus, causal inferences derived from the data are suggestive but not definitive.

Research in both areas has been measurement-oriented, with data gathered for most variables via interview survey and self-report instruments. Most studies employing these methods attend to the need for valid and reliable measurement and coding practices. There is a tendency for researchers to standardize assessments via use of the same instruments across studies, a practice which should allow greater comparison across

different subpopulations. Also, to the credit of the field, research has begun to examine both expressed emotion and burden of care in different nations. Studies included in the above review were completed in the United States, China, Iran, Chile, and India.

There are several areas where research targeting and practices might be improved in the future. Focus on expressed emotion and burden of care, while informative and useful, is relatively narrow, especially if one considers the wider possible impacts of schizophrenia on family members and wider family functioning. As my personal story indicates, it would be useful to expand research to gather data from “key individuals.” Much of the existing research focuses on reports gathered from parents of patients, usually a primary caregiver. The impact of schizophrenia on *children*, in situations where a parent is the patient, has been largely ignored. Much research is currently guided by models of burden and stress that have little, if any, developmental focus. For example, what are the implications of expressed emotion and burden of care for *other* family members – for children, for spouses, for extended family members and friends who may be providing direct and indirect support? What is the impact of the entrance and chronic course of schizophrenia on the multi-level developmental trajectories of children at different periods of childhood? As Reupert and Maybery (2007, pp. 362-363) note, “parental mental illness places children at a significantly greater risk of having lower social, psychological, and physical health than children in families not affected by mental illness.” Some children may face challenges associated with role confusion. Children may have to take on adult tasks in order to help the patient cope with an illness, such as taking care of younger siblings, household duties, and emotional support for the

parent (Mental Health America, 2007). Dealing with these issues may delay or impair normative and healthy development.

Where is the developmental theory that might be applied to the context of family dysfunction that may accompany schizophrenia? My own story indicates that the chronic presence of schizophrenia in a parent may extract a long-term toll on individual family members and on the family as a unit. The application of chronic stress models, fused within an appropriate developmental perspective, seems like a logical and useful suggestion at this point in time. To what extent do modern pharmaceutical and therapeutic treatment options affect the wider ecology of the family, of its individual family members? It would seem that ecological or contextual developmental approaches (e.g., Bronfenbrenner or Magnusson) would widen the perspectives of those guided currently by narrower clinical or adult-centered approaches.

An example of a theory that could provide a solid foundation for researchers is the Family Systems Theory. This would allow studies to be conducted on families as a whole, not just at an individual level. Looking at the family as a whole would benefit cross-cultural research as well. “A genuinely systemic view of families is unavoidably contextual, taking into account the sociocultural, historical, political, and economic matrices in which particular families are located” (Boss, Doherty, LaRossa, Schumm, and Steinmetz, 1993, p. 333).

To a great extent, schizophrenia is a “family illness”. Many times patients are released from the hospital back into the care of their families. Klein and White (1996, pp. 158-159) discuss concepts of the Family Systems Theory. A few of the concepts that could assist medical professionals in helping family members cope with the patient are

setting appropriate boundaries, feedback input and output, and equilibrium. These concepts might have useful application in helping families dealing with a family member that has just been diagnosed with schizophrenia or when dealing with a patient for an extended period of time.

While research has occurred in different nations with varying subpopulations, few researchers have bothered to make cross-cultural comparisons of findings. This is partially due to the separate agendas pursued by different researchers. Some standardization of research purposes may help to allay this practice. Many of the cross-national studies fail to discuss in detail how the local, regional, or national normative culture of illness or deviance may insert itself into the research findings. For example, cultural factors may help us to understand why some families have high or low expressed emotion or level of burden. Latino families may be more involved, and show affection toward the family member that has a mental disorder. In Chinese culture interdependence – not independence -- is stressed in families. Chien et al., (2007) reported that “There is a strong desire in most Chinese individuals to maintain their roles and relationships, thereby enabling the family system to maintain equilibrium. Any occurrence of mental illness and hospitalization of a family member in a mental hospital results in psychological and emotional disturbances for the whole family” (Ma & Yip, 1997). American culture stresses independence as a guiding value. If a family member becomes mentally ill, expressed emotion and burden of care may be high if the patient is not able to care for herself and maintain independence.

I believe my personal story or narrative illustrates several needs not being addressed by current research on schizophrenia and family functioning. Though my story is just

one aspect of growing up around schizophrenia, I know what impact it has had on my family. Family relationships have been destroyed, trust has been broken, and it has left me wondering if my life would have turned out differently if this illness had not been a part of my life as a child. It is my hope that more research will be conducted in this area so that other children who are growing up in a household where they are affected by a mental illness will have a chance to be educated and interventions could be put in place to minimize the effect on the child's developmental stages.

While research to date should be commended for using systematic measurement approaches, the contrast between my personal experience and the existing state of research leads one to believe that several dimensions or variables have been omitted from current research. One wonders, as in the story of the man who dropped a quarter in the dark and looked for it under the street lamp where the light was better, if the rush to do science on this topic has led to a "measurement-rich but construct poor" state of affairs. While expressed emotion and sense of burden are important constructs, many important dimensions remain uninvestigated in the dark. A qualitative approach allowing family members to discuss how the illness has affected them may allow researchers to gain a better understanding of how the disorder affects family functioning. An appreciation of the phenomenology of the lived experience with a schizophrenic parent allows a more sensitive appreciation of the impact of the disorder on children. Questions suggested by my personal narrative include: What types of adaptive responses to children do varying ages use to deal with the impacts of parental schizophrenia? (For example, as a child, I believed that if I cleaned the house and did all of my chores, my mother would be less likely to be hospitalized again. This type of "magical thinking" proved ineffective,

though it is not atypical for a child to cope in this fashion.) From the perspective of a developing child, what losses or disappointments are viewed as most severe? (Clearly, family events involving celebrations and family rituals were among these.) What types of causal attributions do various family members make about what or who is responsible for the loss, sadness, and misery that often occurs in these scenarios? (I tended to blame my mother for her behavior, believing that as an adult she was a free and responsible agent capable of controlling her behavior “if she would only choose to do so.”) How do family members, particularly children, deal with the chronic presence of schizophrenia, and, more specifically, how schizophrenia affect the relationship between the developing child and the parent? What are the “normative” scars that children may be expected to carry forward through adolescence and adulthood? Longitudinal research would help address some of these questions regarding the chronic impacts of schizophrenia on family functioning.

Many of the research articles that were reviewed utilized research tools that did not allow for in depth research of what the actual impact was on the family unit and certainly not the impact on young children. Mothers, fathers, husbands, wives and siblings were the family members used to conduct research in many of the articles. The measurement tools rated answers on a scale, so family members were not allowed to discuss their actual feelings of how this illness is affecting their family. Allowing family members to discuss how the illness has affected them may allow researchers to gain a better understanding of what dynamics in the family were being affected. Also, researching young children, possibly using interviewing techniques and following the

child throughout their childhood to see how they are developing would give researchers better insight into how their childhood development is affected by this illness.

It is clear that practitioners have a strong role to play in families affected by schizophrenia. Family counseling should be conducted with all family members when hospitalization occurs, perhaps sooner if possible. Family education should occur as early as possible upon diagnosis. With permission of the appropriate family head, components of this education should be presented developmentally. They should include familiarization with schizophrenia, behavioral expectations regarding symptoms and implications for individual and family relations, expectations regarding possible changes of normal family lifestyle, predictable emotional and psychological reactions to living with someone who has the disorder, useful strategies for dealing with frustration, fears, anxiety, depression, and conflict resolution, and a long-term plan for receiving consistent support and counseling. Programmatic interventions must be more fully informed by systematic research that attends to the full family context, gleaning consistencies and contrasts from the personal stories of family members dealing with the disorder.

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