2009

A Search for Meaning: The Family's Response to Serious Mental Illness

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A SEARCH FOR MEANING: THE FAMILY'S RESPONSE TO SERIOUS
MENTAL ILLNESS

A dissertation submitted to the Faculty of
Antioch University, Santa Barbara in
partial fulfillment of the requirements for the
Degree of Doctorate of Psychology in
Clinical Psychology with a Family
Psychology specialization and a concentration
in Family Forensic Psychology

By

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Abstract

A Search for Meaning: The Family's Response to Serious
Mental Illness

By

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It is a commonly held belief that it is inherent in
human nature to strive for coherence and meaning in
the midst of adversity. Whether this is short or long
term, for immediate or prolonged functioning, we all
strive to put experiences within events into a
framework that enables us to develop a sense of order
leading to acceptance and resolution. Therefore, each
individual within a family system may develop a
hypothesis in order to make a modicum of sense of what
can appear to be an impossible situation. The
participants involved in this study were individuals
with relatives suffering from mental illness; parents,
siblings, children, and extended family members who
had raised a niece/nephew or grandchild with mental
illness. The research design was based on pilot
interviews, a demographic questionnaire, and a
structured narrative interview. The transcribed texts
were analyzed using structural analysis and grounded
theory. Five women and three men provided narratives
of their lived experience with a family member
suffering with mental illness from a variety of
perspectives in response to open-ended questions posed
by Researcher. The emergent themes were organized and
categorized into levels or stages of experience that
became the structural equivalent of the journey
undertaken by these individuals in their search for
meaning. These themes were characterized by the need
for the experience of feelings, the need to reach out
(personal contact), the need for cognitive process
(faculty of knowing), the need for an end purpose, the
need for an outcome, and the need for an ultimate
resolution from which sense or meaning is derived.
Results of the study indicated that family members

come to terms with or find meaning in the midst of familial
mental illness through a process that incorporates the succinct
concepts of emotion, resources, knowledge, strategies, process,
and coming to terms. The integration of these components into a
model of meaning for families with relatives suffering from
mental illness lead these individuals to ways of being in the
world that is characterized, in most cases, by active engagement
in the search for meaning. The electronic version of this
dissertation is available in the open-access OhioLink ETD
Center, www.ohiolink.edu/etd.

DEDICATION

To Karl, my husband, who is my constant and
dearest friend.

ACKNOWLEDGMENTS

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CHAPTER I: INTRODUCTION

As for me, you must know that I shouldn't precisely
have chosen madness if there had been any choice.
Vincent Van Gogh, 1889

In our society individuals with mental illness
have many demonstrative behaviors, as well as
inclinations toward behaviors attributed to them that
are based on misinformation, flawed perceptions, and
quite often, fear of the true nature of organic brain
disorders. Thus those suffering with mental illness
have become stigmatized (Torrey, 1988, 2001). Families
of individuals with mental illness are often caught in
a negative framework consistent with the prevailing
social perceptions of those suffering from mental
illness as they attempt to deal with the diagnostic
reality of a relative. Coming to terms with such a
tragedy requires the family to change and process its
response to the reality of receiving such a diagnosis.
The journey that each family takes is unique. The
arrival at some point in time to a state of acceptance
of the family member with mental illness involves the
process of developing the acquisition of meaning and

coherence (Antonovsky & Sourani, 1988; Muesser & Gingerich, 2006; Torrey).

As a model for accepting and coping with familial mental illness, meaning provides a context for resolution and reconciliation for family members. This process is necessary for the long-term mental health of all involved and the search provides opportunity for personal growth for each individual in the system. The burden of action is on the family. As they look on and attempt to respond to the best of their ability to the individual suffering from mental illness, the challenge to the family is certain and inevitable (Terkelson, 1987; Rose, 1983; Teschinsky, 2000).

An individual who is struggling with the symptoms of a serious mental illness is unable to critically evaluate the experience and react appropriately. That person is often demoralized and in the depths of despair. That person also lacks insight into the existence of the experienced illness, as well as the wish to be completely well. In the midst of

chaos treatment may inevitably be rejected (Cromwell, 1978; Marsh, 1992; Maxmen & Ward, 1995).

Thus the burden falls to the family to research and organize all of the resources at its disposal in order to find a remedy to such an experience as well as the resolve to access help for themselves and the individual (Goldstein, 1981; Hatfield & Lefley, 1993).

The question that looms is how and where do families of those suffering from mental illness find the ability to make a difficult situation bearable and ultimately hopeful? What functional processes contribute to an end result that is both fulfilling and creates an environment within which both the family and its relative with mental illness can live and relate respectfully to one another? It is the premise of this study that such a destination can be arrived at through the thoughtful pursuit of meaning. There is support for the notion that stressful events and the accompanying need for adaptation centers around certain themes, one of which is the search for meaning in the experience (Marsh, 1992). A family's

response and effective adaptation to such an event is associated with making clear what appears incomprehensible, managing that which feels out of control, and finding relevance in confusion (Rose, 1983).

This study will explore the journey common to all family members in their search for meaning. The end result of which will not only add to the literature but will also be of direct benefit to those who are trying to make sense of their lives.

CHAPTER II: REVIEW OF THE LITERATURE

An important premise of this study is the belief that it is inherent in human nature to strive for coherence and meaning in the midst of adversity. Therefore, each individual within the family system may develop a personal hypothesis with which a modicum of sense can be made of an impossible situation. Whether this is in the short term or the long term, for immediate or prolonged functioning, we all strive to put experiences within events into a framework that enables us to develop a sense of acceptance and resolution.

The Effects on the Family

The onset of mental illness and subsequent diagnosis is invariably a disaster. All family members are victims. It affects attitudes toward self and life. It produces physical and mental symptoms of illness in other family members. It alters the systemic structure of the family, influencing a multitude of present and future life choices (Terkelsen, 1987).

"Families continue to be the primary caretakers of the mentally ill" (Johnson, 1990, p. 31). The objective burden of families is described as including the troublesome behaviors of the individual, disruptions of daily routines, interference with social and leisure activities, and demands on family time and effort. The subjective burden is defined as the emotional impact of living with a family member with mental illness. As primary caretakers, family members may initially experience shock. They find themselves in a state of ambiguity. The ability of these families to cope and adapt, and make functional changes often depends upon the availability of supportive networks, psychiatric and psychological services, and family management (Johnson).

Children, Siblings, and Parents

Children of parents with mental illness take on a great deal of emotional responsibility as they care for their parents. In fact, the impact of this tremendous responsibility on the long-term psychological health and well-being of these children

is still not fully understood. It is clear however that the ongoing experience and development of these children is adversely affected (Aldridge, 2006).

Parental reaction to their children with mental illness involves worry, financial concern, stress, anxiety, resentment, grief, depression, stigmatization, disruption of family social life, guilt, and self-blame. There is profound disruption for all involved in the family.

The burden undertaken by the family with a relative who suffers from mental illness, whether it be parent, child or sibling, is highlighted by the following themes: loss of what might have been, fear, grief, shock, confusion, and negative self-blame. Contributing to the family burden inevitably is the behavioral repertoire of the individual. These behaviors can include a myriad of challenging aspects including withdrawal, verbal aggression, violence at times, unwarranted suspicion, and poor self-care. Parents often search for meaning in an attempt to explain the precipitation of a mental breakdown and

subsequent diagnosis of a child (Ferriter & Huband, 2003).

Parents feel responsible for the welfare of their children suffering with mental illness. They want to be of help to them even through adulthood. Common reactions and feelings reported by parents are helplessness, confusion, frustration, guilt, sadness, embarrassment, and anger. Siblings have similar reactions but also have unique perspectives. The illness of a sibling evokes confusion and frustration, anxiety about developing the illness, distress, feeling self-conscious, resentment and anger, and survivor guilt. Only by balancing the needs of self and other can there be forward movement. Becoming knowledgeable about the illness and understanding the effects on the family can minimize the feelings of being alone in the experience. Serious mental illness will impact, but does not need to dominate, the lives of everyone involved (Muesser & Gingerich, 2006).

Adult children and siblings experience the mental illness of a relative as a cataclysmic event.

The impact of such an experience pervades their entire lives. Siblings and adult children often report however that they have "more than merely survived" (Marsh, Appleby, Dickens, Owens, & Young, 1993, p. 29). They report that as a result of their intimate experience with mental illness they were more compassionate and stronger as individuals. Resources for developing coping skills, adaptation, and resilience to chronic trauma were found in family, friends, and professional support groups such as NAMI (National Alliance on Mental Illness) (Marsh, et al.).

Appraisal Process

As families react to the trauma and victimization of having a relative with mental illness a number of things begin to happen. The family members start an appraisal of the situation as well as an appraisal of the personal issues that are true for them. This appraisal process is actually the beginning of developing coping strategies for how they will deal with the situation at hand; in the present and in the future. Some of the personal factors that may

influence a person's understanding of the event may include commitments and beliefs about that individual's personal control, as well as existential issues. As this appraisal progresses, the significance of each personal factor is evaluated as it relates to the event. These personal factors tend to interact with situational factors and influence the outcome of the process. The situational factors: novelty, predictability, event uncertainty, imminence, duration, and temporal uncertainty work to explain the process of appraisal that has been set in motion. As individuals begin to come to terms with their family's situation, they are attempting to assess what will be required of them in terms of commitment and for how long (duration), the uncertainty of the future, and their own lack of personal control over circumstances. The interpersonal process required to maintain the status quo of the family system is not amenable to the individual even though this may continue to be an expectation of the family. The complexity of the situation becomes apparent and the stress inherent in

the upheaval caused by mental illness should ideally

lead to developing workable coping strategies

(Terkelsen, 1987).

Defenses

The coping strategies that each family member is

able to bring about through that individual's personal

experience will determine how the inevitable will be

manageable.

A natural response to stress is defensiveness.

Defenses act as a natural protection to unexpected

life events. We each possess a psychological integrity

that demands protection from pain that may be

experienced. Defenses serve a number of purposes

including maintaining affect within acceptable limits,

containing such drives as sexuality and aggression,

mastering changes in self-image when there is a lull,

and mitigating unresolved conflict (Terkelsen, 1987).

The defensive mechanisms that are in operation

at this time fall along a continuum and range from

pathological to adaptive. These defenses fall into the

following categories: psychotic, immature, neurotic,

and mature. The manner in which the family member conceptualizes the stress that is being experienced and defends against it, will determine the potential outcome of the coping process. The protective function of defenses can reduce or limit such effects as overwhelming anxiety (Terkelsen, 1987).

"Mental illness is a catastrophic event for families" (Marsh, 1992, p. 137). The response of families to the existence of mental illness in the individual can be both healthy and pathological. There are aspects of family functioning that are both resourceful and inadequate. Coping strategies exhibited by the families with members who suffer from mental illness are similar to those strategies in use by families dealing with significant problems other than mental illness. However, in the families who have relatives with mental illness the problems are, for the most part, more intense, chronic, and more demanding than situational problems encountered by families who do not (Marsh).

It has been discussed that serious mental illness is a catastrophic event that affects all members of a family. Serious mental illness, when defined as a family burden only, increases the risk of ignoring other important dimensions of the family experience. The experiences identified are the subjective burden (personal suffering), the grieving process (mourning the relative they knew and loved), symbolic loss (hopes, dreams and expectations), chronic sorrow (feelings waxing and waning across course of illness), the emotional roller coaster ride (relapse, remission, turmoil, renewed hope), and empathetic pain (the corporate loss) (Marsh & Johnson, 1997).

Coping Strategies

As human beings, we cope with a myriad of experiences and events every day. How we categorize or appraise these events may determine how we respond. If an event is determined to be stressful then our coping mechanisms are triggered in order to manage the demands that are made on our internal and external

worlds. If the event is appraised as being beyond or exhausting our resources, then our coping response is activated. We may alter or just manage the problem or event. Such coping is considered problem-focused. If the focus is to regulate the emotional response, such coping is considered emotion-focused coping. This may appear obvious, but the coping is determined by available resources as well as any constraints that are in operation (Terkelsen, 1987).

The experience of the family member involves both the objective burden (consisting of reality-based problems) and the subjective burden (perceived problems and emotional distress). Siblings, young children and adult children living in a family setting with mental illness as a constant presence, describe a range of ambivalent feelings and attitudes toward their loved ones. Families trying to cope with the demands of mental illness report substantial difficulties with balancing the needs of the family and managing their own responses to the problematic behavior of the individual (Hatfield & Lefley, 1993).

"Mental illness is, by its very nature, a familial experience" (Teschinsky, 2000, p. 387). Families feel isolated and blamed. Their lives are interrupted. Families are the first to notice a loved one is ill. Their initial response is a range of emotions such as anger, shame, guilt, resentment, sadness, and panic. Long term, families develop coping behaviors. Certain strategies and themes have emerged for living with and coping with the emotional reaction to the illness and the prolonged feelings of burden, loss, and grief (Teschinsky).

Mental illness accounts for the most years lived with the impact of a disabling disease by the family, with the only exception being heart disease. With this astounding fact, the question arises: What is the resulting quality of life overall for these families affected? To answer this question, it is necessary to examine the three phases proposed in this study that these families go though in caring for individuals with mental illness. These phases are: Hanging On (uncertainty and frustration); Stable Families

(adequate support), and Doing Well Families
(possibilities and opportunities). Walton-Moss,
Gerson, and Rose posit that identifying the
characteristics of families in different phases will
help in the identification of each phase and the
prioritizing of the needs for professional
intervention and social support that is necessary to
make an enhanced quality of life not just a
possibility, but a present reality (2005).

Mental illness is a familial experience which
includes siblings and offspring. Noted coping skills
utilized by these family members include constructive
escape, a positive outlet which has no negative
repercussions. Conversely, destructive escape,
although allowing for more immediate relief, is
generally considered more negative in effect.
Unfortunately, siblings and offspring commonly tend to
remain without the services that would assist them in
coping with and adapting to mental illness, and they
are left to draw on personal resources and strengths
(Kinsella & Anderson, 1996).

Families have important adaptive capacities. They can play a crucial role in rehabilitating the individual. When supported by their social environment they are more effective in their ability to cope. The outcome of effective coping is competence. Competence results in increased family functioning (Goldstein, 1981).

<center>*Mediating Variables*</center>

It has become apparent that the families who have relatives suffering with mental illness may function effectively and successfully under the influence of certain psychosocial variables or factors. Some of the variables that have been identified are the ability to cope, the amount of psychological distress and caregiver burden, social support, caregiver resilience or caregiver depression, and the frequency and extent of behavioral problems presented by the individual with mental illness. In order to improve the quality of life in families living with mental illness, it is of extreme importance to investigate the parameters of this

knowledge and ensure the effective functioning of the affected family system (Saunders, 2003).

Resources may include health and energy, problem-solving skills, social support, and existential beliefs. Constraints may be personal and include internalized cultural values and beliefs, or environmental, including competing demands. As the level of threat increases, an individual can be prevented from utilizing personal resources for coping efficiently. As family members become overwhelmed and the experience is appraised as threatening, harmful or too challenging they may find themselves unable to respond to their family member in a productive and useful manner. Over the long-term this is not predictive of healthy or beneficial interactions between the fatigued family and its relative with mental illness (Terkelsen, 1987).

Significant developments in theory, research and practice concerning families with members who suffer from mental illness have more recently increased enormously, as well as the acknowledgment of the

contributions and expertise of families in the acceptance, care, and treatment of their relatives with serious mental illness.

There are effective intervention strategies available for families to utilize as they deal with their grief, which increases the potential for competence and mastery even as the integrity of the family is under assault (Marsh, Lefley, & Husted, 1996).

The family experience comes from the meaning it is able to attach to mental illness. There is an explanation for the behavior of the relative with mental illness and this explanation erases the artificial barriers of race, sex, and religion. The explanation can be scientifically derived, culturally derived, or experientially derived; but the acceptance that follows is based on many complex factors. Some of the factors that have been identified are the importance of previous beliefs, the notion of cause and cure, the perception of stigma, and attitudes about the future (Rose, 1983).

The Legacy

As the family proceeds through life with the diagnosis of schizophrenia, bipolar disorder or major depression before it, the legacy of such diagnoses and their attending symptomatology is oftentimes too powerful. Families find that their coping skills and strategies are not sufficient to counter the enduring effects of mental illness and they may resort to what is easiest rather than what could ultimately bring healing to the family. The daily problems and challenges prove to be an overwhelming burden.

Each family member has varying abilities for coping with the relative who has mental illness. Some will appear to rise to the occasion with very little effort and demonstrate a capacity beyond that individual's years to adapt to the grief, confusion, and shame of his or her relative's disease. For those who can see nothing positive for a family affected by mental illness, who have a sense of anger or disbelief over something which is beyond their control, there are mediating variables that can lend considerable

hope and encouragement. Such variables are different dimensions of the family's resilience: family bonds and commitments, family strengths and resources, family growth and development, family contributions, and family gratifications. There are also personal resilience variables that an individual member may exhibit: personal contributions, improved personal qualities, personal growth and development, enhanced coping effectiveness, personal gratifications, and better perspectives and priorities (Terkelsen, 1987).

The Search for Meaning

As the families who have relatives with mental illness approach the devastating illness of their relatives, they are not unlike any one in a situation of similar stress. When we find ourselves in incomprehensible circumstances we attempt to attach meaning and coherence to an otherwise befuddling situation (Antonovsky & Sourani, 1988).

"This terrible illness colors everything -- a family member cannot escape" (Marsh & Lefley, 1996, p. 3). At the core of the experience is chronic sorrow.

The family mourns for the loved one it <u>has</u> known. Nevertheless, families can exhibit resilience and the ability to rebound from adversity and prevail over the direst circumstances of life. Family members can become people of substance who do not crack and disintegrate under the weight of mental illness. They can present with mastery, dignity and empathy as they meet and deal with daily problems and challenges that were never invited nor anticipated (Marsh & Lefley).

Since deinstitutionalization, families have often become the primary care givers for their relatives with mental illness. As discussed there is significant grief and a sense of loss associated with the illness. In order to survive as a functional unit, and to be able to provide the best care possible for the individual with mental illness, families must have hope. Families trying to cope in the midst of chaos must recognize the need for self-care. The concept of self-care may not be immediately apparent to families trying to just survive a multitude of monthly, weekly and even daily crises. It is imperative that the

impacted families find social support, professional support, and be educated in developing ideas and skills for successful coping. Families need to be assured they are capable partners in the process of intervening in the life of the individual (Pollio, North, Reid, Miletic, & McClendon, 2006).

CHAPTER III: STATEMENT OF THE PROBLEM

Main Research Question

The question of interest to be explored in this study is: How does the family find meaning in response to the diagnosis of a family member with mental illness**?**

Objectives

The objectives of this study are to explore and formulate a model of meaning for families who are struggling with the experience of a relative suffering from mental illness. Ultimately, such information would prove useful not only to families but also the mental health system and advocacy groups.

CHAPTER IV: METHODS

The participants taking part in this study were family members of individuals with mental illness. Because the original family was the unit of study the family members who participated were parents, siblings, children, and extended family members who had raised a niece/nephew or grandchild with mental illness.

The method of selection included recruitment from local agencies (private, governmental) serving the population of individuals with mental illness, i.e. The Mental Health Association of Santa Barbara, the local chapter of National Alliance on Mental Illness, Santa Barbara County Mental Health, Sanctuary Psychiatric Facility, and Phoenix of Santa Barbara. Participants were also recruited by word-of-mouth. A letter of introduction (Recruitment Letter, Appendix E) and a flyer (Recruitment Flyer, Appendix F) were sent to these locations soliciting participants, and was also provided to the Family Advocate for circulation at a local NAMI (National Alliance on

Mental Illness) meeting on March 27, 2008. Criteria for participation included age (18 years of age or older), willingness, a basic understanding of the objectives of the study, functional reading level sufficient to complete a demographic questionnaire (determined by administration of the WRAT-IV-READ), psychiatric stability (determined by administration of the BDI-II), and having a relative in the immediate or extended family with a schizophrenia spectrum disorder, bipolar disorder, mood disorder, or anxiety disorder (as defined by DSM-IV-TR criteria). Eight participants were ultimately interviewed. The participants were individuals who were seeking or had sought help or support for dealing with a relative with mental illness.

Instrumentation used was the BDI-II (Beck Depression Inventory), the WRAT-IV-READ (Wide Range Achievement Test), a demographic questionnaire, and an unstructured interview of 10 open-ended questions. As individuals demonstrated interest in participation (via phone call or email) the Researcher mailed a

packet of paperwork to potential subjects requesting that documents be returned via an enclosed self-addressed stamped envelope. The packet included a Recruitment Letter and Recruitment Flyer, a Consent Form, a Demographic Questionnaire, and a BDI-II (Beck Depression Inventory). Documentation returned to the Researcher was reviewed and if the individual met participation criteria, the Researcher contacted each individual to schedule a personal (1:1) interview. At the time of the interview a WRAT-IV-READ was administered by the Researcher to participant and the 10 interview questions were posed for participant response. All 1:1 interviews were recorded via digital voice recorder for accuracy of data collection and transcription. The Researcher also took brief notes which included preliminary coding impressions.

Each participant was interviewed 1:1 by the Researcher. The interview was a battery of 10 pre-determined, open-ended questions that were asked of each participant. The questions were developed by the Researcher and approved by her committee. The

questions were designed to elicit information to answer the main research question. The length of each interview was an average of 52 minutes. A pilot study to test the research design including interview questions was conducted with 2 participants prior to commencing the actual study itself.

<div style="text-align:center">Procedures for the Study</div>

1. Recruitment of participants was accomplished via letters, flyers, and word-of-mouth.

2. The location for three interviews was Antioch University, another two were conducted in the participant's private offices, and another three took place at a church convenient to participants who resided nearby. All locations guaranteed confidentiality to the extent that all participants were interviewed singly in closed rooms with limited access from the outside.

3. Participants were required to complete, or have administered to them, a BDI-II, a WRAT-IV-READ, a Consent Form, a Demographic

Questionnaire, and a 1:1 interview with the Researcher.

4. Each participant who agreed by telephone to participate in the study then received by mail a Recruitment Letter (Appendix E) that explained the nature of the study as well as expectations for involvement (time commitment, duration of availability for possible follow-up), a Recruitment Flyer (Appendix F), a Demographic Questionnaire (Appendix C), a BDI-II (Beck Depression Inventory), as well as a Consent Form (Appendix A). Participants were required to complete and return all paperwork prior to scheduling any interviews.

5. Researcher mailed via U.S. postal services, emailed, and distributed recruitment letters and flyers, interacted with possible participants via phone or e-mail, assessed for inclusion in study, administered the WRAT-IV-READ, prepared Consent Form and Demographic Questionnaire, provided the BDI-II (Beck

Depression Inventory) for participant self-administration, scheduled 1:1 interviews with participants, and conducted interviews.

6. Interviews conducted were: 1) the 1:1 30-90 minute data collection interview conducted by the Researcher with participant; and 2) a final optional interview of approximately 15 minutes conducted by the Researcher with participant for debriefing purposes only.

7. The Researcher responded via telephone and email to interested parties. The data collection interview was scheduled as soon after receipt of paperwork as was mutually acceptable. The final optional interview was scheduled after the data collection interview, at the request of participant, and as soon as was mutually agreeable.

8. Data was collected via one interview conducted by the Researcher and one paper and pencil questionnaire completed by participant. Data collection interview only, was recorded to

ensure accurate collection and transcription of data.

9. Data collected was interpreted via standard qualitative data analysis procedures. Such analytic methods included: affixing codes to notes drawn from interviews; noting reflections/remarks in the margins; identifying similar phrases, patterns, themes, and common sequences; isolating patterns/processes, commonalities/differences; elaborating a small set of possible generalizations; and confronting generalizations with a formalized body of knowledge.

10. Pilot study to test validity of interview questions was conducted with 2 participants who met criteria and expressed willingness and interest to take part in the study.

Data Processing Techniques

Qualitative inquiry is the study of human group life (Denzin & Lincoln, 2003). As a qualitative

researcher I was operating as a *bricoleur*—a maker of quilts. I was creating a montage of images collected from the minds of my participants.

"Data analysis is the process of moving from raw interviews to evidence-based interpretations…" (Rubin & Rubin, 2005, p. 201). This included classifying, comparing, weighing and combining interview material to extract meaning and implications, to reveal patterns, and to sew up descriptions of events into coherency.

The first step was to prepare the transcripts for finding, refining, and elaborating concepts, themes and events, and coding the interviews for retrieval of the concepts, themes and events that had been identified. These concepts were compared or combined. The ultimate goal was to answer the research question and possibly draw broader theoretical conclusions.

Analysis was ongoing. It began in the interview and continued from the transcription of the interview to the notes taken by the Researcher as the subject

was interviewed. Once the interview was completed however, a detailed line-by-line analysis was necessary to generate initial categories, suggesting relationships among categories. This was an examination of single words, phrases, and sentences, looking at the details in a descriptive sense, as well as an analytic sense, making comparisons along the levels of properties and dimensions in order to break this down into an interpretive scheme. This also included listening to what the interviewees were saying and how they said it. What might their interpretation of events have been?

It was important to read each interview carefully before going on to the next in order to begin to formulate a working idea of important concepts, themes and events. These concepts, themes and events were then examined across the different interviews for an initial combination of material that began to suggest a description of what was happening and the possible meaning. Organization of the data into discrete categories according to its properties

and dimensions and then using that description to identify those categories was the process of coding. Codes are the distinct label used for concepts, themes, events or topical markers. Descriptions included objects, people, scenes, events, actions, emotions, moods, and aspirations.

There was an overall relationship between codes, called the code structure, and creating a provisional list at the outset of research using published literature for suggestions is commonly accepted and was undertaken by the Researcher. This list came from the conceptual framework of the study, the research questions, hypotheses, or identified problem areas. The start list had a number of preliminary codes, but by the end there were as many as 50-60 codes. Codes required definitions which became clear as the study proceeded, and in fact the codes changed and developed as the research continued. Ultimately some codes did not work and others needed to be broken down into sub-codes because too many segments in the transcript got the same code. Coding and recoding were over when the

analysis had run its course; "when all of the incidents can be readily classified, categories are 'saturated,' and sufficient numbers of 'regularities' emerge" (Miles & Huberman, 1994, p. 62).

The specific approach to developing codes included looking at the explicit terms used in the interview questions. Also, looking for concepts, themes, etc., that were explicitly raised by the interviewees was an important element of this process. More subtle concepts and themes were found by reflecting on implied meaning as well as what might have been more indirectly revealed, such as through the tension between the emotions expressed and the words that were spoken. If an interviewee stated that he or she was no longer bothered by a particular event but the pain in his or her voice was obvious, a theme was deduced from this contradiction. It was called *denial of pain*. Comparing interviews was useful, specifically what each subject said about the same issue(s). Were there contradictions and why? Existing concepts and themes suggested new related concepts and

themes. For instance, two responses from different subjects appeared to be linked—this linkage suggested a new theme. Concepts were grouped together to see what they collectively implied. Also looking at what was already worked out called to mind what was missing. For instance, if one were studying social science majors and was coding for psychology, sociology, anthropology and economics one might ask if any other majors that existed in social sciences had been covered. Concepts and themes for coding purposes were found in figures of speech ("Holy cow!"), slogans ("Each one, reach one, teach one, recruit one"), and symbols ("NAMI").

Creating consistent and refined definitions of the developed codes required asking a series of questions. Such questions included: *What am I going to call it (label it)?; How am I defining it?; How am I going to recognize it in the interviews?; What do I want to exclude?;* and *What is an example?*. The Researcher necessarily tried out the definitions on a sample of interview transcript to make sure that they

worked or whether they needed further refinement. For example, the term *community* may have referred to both the physical neighborhood and an ethnic affiliation. Each connotation required a different label.

Physically coding the data involved going through the transcripts and placing a code or label next to each data unit where the matching concept, theme or event occurred. Good definitions facilitated this step. The mechanical process of coding was a matter of personal style. It can be done in the margins of the transcripts or it can be done in the text within brackets, for example **["9/11"]**, or simply by darkening or highlighting the key words to look at later. The Researcher used a variety of these methods.

Analyzing coded data can either be done with a word processor ("finding" recurring codes or labels) or by using specialized software (Orbis, NVivo, QDA Miner, etc.). The Researcher utilized the features of the word processing program for this step of analysis. Building toward narratives and descriptions of the research involved sorting and summarizing coded data,

sorting and ranking coded data, sorting and comparing coded data, weighing and combining coded data, and finally integrating, checking and modifying coded data.

Ultimately the Researcher wanted to create a solid base for writing the narrative and descriptive parts of the study which would lead to broader implications of what had been learned, usually described as theory. Most qualitative researchers use middle-level theory that builds on what has been learned from the interviews and speaks to issues present in the literature. The Researcher used the *grounded theory* approach to research in this study, wherein the theory emerged from data which was systematically gathered and analyzed. This type of theory tends to resemble reality more closely because it is drawn from the data rather than beginning from a preconceived theory based on experience or a personal speculation of how things ought to work. In grounded theory one can step back from the analysis and contemplate how insights derived from this process

have come together to form a meaningful theory that explains a more expansive part of the culture or offers an explanation of why events developed as they did (Denzin & Lincoln, 2005; Miles & Huberman, 1994; Rubin & Rubin, 2005; Strauss & Corbin, 1998).

Methodological Assumptions and Limitations

Typically, results and hypotheses of qualitative studies are cautiously generalized to the population at large. Grounded theory however is about building theory rather than testing theory and is therefore less focused on limitations and generalizations. Studying the population of interest in the small community of Santa Barbara and its environs limited the variability of participants however. Specifically, the participant population that was ultimately recruited was comprised of seven Caucasian adults and one Asian-American adult. Ideally further research in other locations would draw on the inclusion of individuals from more diverse backgrounds (racial, ethnic, religious, SES, sexual orientation, etc.) and

therefore continue to support the working hypothesis of this study.

Ethical Assurances

This study abided by the standards published by the American Psychological Association in their 10 principles for the conduct of research with human participants. The dignity of each participant was protected as well as the confidentiality of each individual's identity and the information that they provided to this study (an identifier code was used for each participant instead of names). All data was kept in a secure location (a locked file box or password protected computer file) during the study and will be destroyed when the study is complete. Participation in this study was voluntary and therefore anyone could remove themselves at any time. All attempts were made to mitigate the effects of the material being explored, and participants were provided with an optional debriefing session at the end of data collection (the 1:1 interview) as well as being provided with referrals to licensed therapists

in the area if they chose. Debriefing was individualized to meet the needs of each participant and was conducted by the Researcher with the intention of providing closure. This final interview was not part of or included in the study. Form B is attached herein, "Insuring Informed Consent of Participants in Research."

CHAPTER V: RESULTS

Eight adults (3 men and 5 women) from a small community in southern California were interviewed for this narrative study formulating the concept of meaning in families who have relatives with mental illness. The mean age of the participants was 59.5 years.

The mean length of the interviews was approximately 52 minutes with interviews ranging from 33 to 91 minutes, and the interviews resulting in a total of 46 transcribed single-spaced pages. The Researcher reviewed and analyzed the interview texts according to set determinants. The texts were then arranged on progressive levels to identify "units of meaning", and these "units" were then categorized into themes. The themes were found to be: a) emotions, b) resources, c) knowledge, d) strategies, e) process, and f) coming to terms.

Participant Profiles

Each interview was comprised of 10 pre-determined questions that were designed to elicit the

experiences of the individual who had lived with familial mental illness. Each individual subject profile is presented in this report in order to provide a semi-biographical context for the participant as well as to present the larger context for the results of the study. Pseudonyms were selected by the Researcher for each participant to ensure confidentiality. Information that could possibly identify a participant was likewise disguised for the same purpose.

Table 1 offers a concise description of the demographic characteristics of the participants.

Charlotte

Charlotte is a 68-year-old Caucasian female with some college education. She was formerly employed in the administrative/clerical field but is currently retired. At the time of this interview she was married with four grown children. She was very talkative during her interview and appeared comfortable as she shared the story of her two children with mental illness.

Table 1
Participant Demographic Information

Name	Age	Gender	Race	Education	Income	Employment Status	Occupation	Marital Status	Children
Charlotte	68	Female	Caucasian	Some College	$85K-104,999	Retired	Clerical/Admin	Married	4
Chris	33	Male	Asian-American	College Graduate	$65K-84,999	Employed Fulltime	Engineer/Architect	Divorced	0
Debra	75	Female	Caucasian	Professional Degree	$45K-64,999	Employed Fulltime	Healthcare/Mental Health	Married	5
Dennis	68	Male	Caucasian	Professional Degree	$85K-104,999	Employed Fulltime	Teacher/Professor	Married	4
Helen	57	Female	Caucasian	Professional Degree	$25K-44,999	Employed Fulltime	Healthcare/Mental Health	Divorced	1
Jennifer	57	Female	Caucasian	Some College	$45K-64,999	Employed Part-time	Human Services	Married	1
Marie	59	Female	Caucasian	Other-M.A.	$85K-104,999	Unemployed	Accountant	Married	3
Tom	59	Male	Caucasian	Professional Degree	$85K-104,999	Employed Fulltime	Manager/Executive/Business	Married	3

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She was 37 years of age and her second son was 4-years-old when she began noticing "unusual behavior and strange speech patterns." After incorrect diagnoses of schizophrenia spectrum disorders, her son was given an autism spectrum diagnosis when he was age 5. Her son eventually began exhibiting obsessive-compulsive behaviors in early childhood and was described as having several severe bouts with OCD throughout his lifetime. His obsessions have typically been centered on contamination or "scrupulosity", an extreme response to and/or approach to religion and religious rituals/behaviors.

Charlotte's son received psychotherapy wherein he learned and continues to learn and to utilize skills to cope with his OCD. Charlotte describes her only daughter and second oldest child, as "such a difficult kid." Charlotte reports medical complications during the pregnancy with her daughter including a number of hemorrhages which were life threatening to both mother and child. When the baby was born she did not breathe at the outset due to

underdeveloped lungs. She recovered from this setback however as she grew older and was ultimately diagnosed with a borderline personality disorder and depression when she was in her thirties. She has continued to be a challenging individual whom Charlotte deals with by creating emotional and physical distance between herself and her daughter. Throughout the interview Charlotte would occasionally laugh when describing the difficulties of raising two children with mental illness. This may have been a coping skill she developed to deal with the pain of her circumstances.

Chris

Chris is a 33-year-old Asian-American male and a college graduate employed full-time as an engineer. At the time of this interview he was divorced with no children. He appeared comfortable telling his story although he also appeared to be mildly anxious. This young man was raised by a father who had profound hoarding behavior. Chris was approximately 8-years-old when he became cognitively aware that his father's excessive collecting was out of the ordinary; however,

he did not think of his father's excessive collecting as abnormal—"I just thought he was weird, you know?" His father's tendency to keep everything was seen as frugal (the father's parents grew up during The Depression) or eclectic ('one man's junk is another man's treasure'). Chris did not recall an official diagnosis of obsessive compulsive disorder having been given to his father; it just became evident to him over time that his father's obsessive collecting behavior was outside the parameters of 'normal' behavior. He remembers that most of his family's neighbors were tolerant. However, Christ recalls a particular neighbor would stand outside the house taking pictures to send to the authorities (the City) and incidents such as these were very uncomfortable for him. "There's a lot of shame involved" he stated. Chris has three siblings, 2 brothers and 1 sister, and he said "…we all left the house as soon as we could to get away from it all." He admits to rarely going home and "my other siblings, never."

Debra

Debra is a 75-year-old Caucasian female with a Master of Arts degree who is a licensed Marriage Family Therapist in private practice. At the time of this interview she was married with 5 grown children. She appeared comfortable as she told her story. She was succinct and clear in her narrative. Debra was 34-years-old when she began to notice her oldest son, at age 10, was different. Because he was not diagnosed until adulthood she describes an existence of having to develop strategies, looking for something that would help her son because his behavior was so out of control. By the time he was diagnosed with bipolar disorder he had been self-medicating for years with illicit substances. Debra felt that the substance abuse co-occurring with a mental health diagnosis exacerbated his symptoms and contributed to her son refusing to seek or accept professional help for a great many years. She related how her son would become aggressive and threatening at times while manic. This was fear-provoking for her and for her husband.

Ultimately she just continued with daily life. "I went back to school. I was involved in my own therapy. I became a therapist. You know, it's just been a process."

Dennis

Dennis is a 68-year-old Caucasian male with a professional degree (Ph.D.) who is employed full-time as a teacher/professor. At the time of this interview he was married with four grown children. He was highly verbal and articulate, and appeared comfortable as he told his story. Dennis has two grown children who have been diagnosed with a mental illness. Dennis began to notice something unusual about his son in infancy because he did not "cling" and when he was in pre-school he tended to isolate himself from the other children. His son was diagnosed first at age five with either "autism" or a "central nervous system dysfunction with characteristics of autism." Dennis reports coming across "Asperger's" in his efforts to educate himself about his son's disability and after reading about the symptoms concluded "that's him." His

son eventually was diagnosed with co-occurring obsessive compulsive disorder in early childhood which was treated via behavioral psychotherapy.

Dennis's adopted daughter was not diagnosed with a personality disorder and depression until she was an adult. "It never had occurred to me that I should never have gotten into this whole thing…I don't really even think of us as a blended family." He is devoted and committed to his family in spite of the difficulties he has experienced with these, now, two adult children.

Helen

Helen is a 57-year-old Caucasian female with a professional degree (M.A.) and is employed full time in the mental health field. At the time of this interview she was divorced but living with someone in a committed relationship. She has one grown child. She appeared comfortable as she told her story about her son and his journey with bipolar disorder. Helen's son was away at college working on his undergraduate degree when he was first diagnosed. He was 21 and she

was 50. She describes this event as "life changing" and stated that it influenced her decision to pursue a graduate degree in clinical psychology. Helen felt that she was fortunate in her experience with her son because his friends at school had already noticed his unusual behavior and served as a resource for her. One friend in particular had experience with a relative's mania and knew to get him professional help immediately. Walking with her son through this experience, she said, created an unbreakable bond between them. This connection provided "insight into his soul" that would later assist her in supporting him when he needed it the most. Helen also spoke about having otherwise gone on with her life and getting past the self-blame of "What signs did I miss?" and "Oh, my God, it's my family."

Jennifer

Jennifer is a 57-year-old Caucasian female with some college. She is employed full-time in the field of human services. At the time of this interview she was married with one teenage child. She appeared

comfortable as she told her story although became tearful in response to a re-stimulating memory that was brought up during her narrative. In her lifetime her sister and her sister's son would ultimately be diagnosed with a mental illness; her sister with bipolar disorder when she was approximately age 30 and the son with schizoaffective disorder when he was 15-years-old. Jennifer ended up raising her nephew because her sister was too ill to raise her child. Jennifer was married when she took on the responsibility of parenting her 4-year-old nephew but did not have any children of her own at the time. "Yikes! That was a big step." She described the experience of familial mental illness as a catalyst for her eventually working in the mental health field, to "help other people." Jennifer also spoke about "the hand dealt in life" and how difficult it was to let go and accept that she really did not have any control over the circumstances much less the two lives most impacted by mental illness in her family.

Marie

Marie is a 59-year-old Caucasian female with a Master of Arts degree. She was formerly employed as an accountant but is currently unemployed in order to be available for her son, "I'm literally on call 24/7. So if my cell phone goes off, I'm going to answer it." At the time of this interview she was married with three grown children. She described herself as clinically depressed but appeared comfortable telling her story, including making self-disclosures about her 20 years of sobriety. Her son was diagnosed when he was in high school following an observable personality change along with behavioral differences that began in late grammar school. Marie spoke about how profoundly altered his character became when he first began presenting with symptoms of mental illness. Prior to this she described him as being a kind and thoughtful boy who took to heart other people's pain or distress. At first he was misdiagnosed with major depression but eventually was correctly diagnosed with paranoid schizophrenia as a 14-year-old. After a succession of

hospitalizations and medication changes, Marie's son had acquired a level of stability such that by age 21 he was fairly stable. He also demonstrated an understanding of the importance of proper and consistent medication by articulating that this was the key to his continued functional mental health. Marie's personal Christian faith has been a mediating factor in this very difficult experience.

Tom

Tom is a 59-year-old Caucasian male with a professional degree and employed full-time in a managerial/executive capacity. At the time of this interview he was married with 3 grown children. He appeared comfortable telling his story. At times he was very matter-of-fact and at others more expressive, "O my God, you know, we really have this thing we gotta deal with." Tom described when he had to have his son hospitalized on his son's 16th birthday as the worst day in his life, "It was horrible. It was horrible." He spoke about how it was easier for him than for his wife to deal with the ongoing situation

because he could just go to work for 8 hours, but she

was in the thick of it day in and day out.

The Participants

The individuals in my study were in many ways

homogeneous but at the same time varied. All of them

were educated; having from "some college" to a

doctorate. All were or had been employed in white-

collar professions, three in mental health. All but

one had children but not all were reporting on an

experience with a son or daughter with mental illness.

As a whole this cohort of participants exhibited

remarkable resilience in their stories of living with

relatives who suffered from mental illness. They each

had strengths and weaknesses which they either used as

an advantage in their pursuit for significance or

recognized as an opportunity for exploring

alternatives in responding. These participants also

portrayed a diversity of experience as they undertook

to deal with relatives who suffered from mental

illness. Each had a slightly different approach in

arriving at the same goal but the same motivation. For

the most part, they each managed to find meaning in their experience.

The Search for Meaning

The objectives of this study were to explore and formulate a model of meaning for families who have struggled or are struggling with the experience of familial mental illness. The Researcher hopes that the findings of this study will prove useful not only to families but also the mental health system and advocacy groups in informing treatment and services for those suffering with mental illness.

As the interviews proceeded and themes began to emerge, there were a number of categories that took shape and began to define the concept (construct) of the search for meaning. These included: (a) emotions; (b) resources; (c) knowledge; (d) strategies; (e) process; and (f) coming to terms.

Emotions

As Charlotte began her story she recalled the difficulty of telling family and friends about her son's diagnosis. Their reactions tended to minimize

the reality of the situation or were indications of

their own personal discomfort; "…some people just

denied it", "…there's really nothing wrong with him",

or "Well, he's not so bad." She also had to deal with

mounting personal guilt in the "implication that we

were not good parents, or that I was not a good

mother." Her son's behavior at the time was "pretty

much out of control". It was "just a disaster" and

"really painful." Efforts to help her son have a

normal childhood included having him play soccer as a

seven-year-old, "And he did not like us for that":

> He couldn't you know, just get it. And he was on
> a team with a coach…that was just hell-bound for
> winning. Every kid had to play at least twenty
> minutes…he did not want to have [my son] play.
> Well, that experience began to be in evidence in
> other areas, you know, he wouldn't be put in the
> school choir, or he wouldn't…be picked for
> stuff. Well, whether he cared or not, I cared.
> And it was very hard for me.

It was also "super difficult" for Charlotte to

deal with her son's emerging OCD, which resulted in

"embarrassing experiences" but also instances, such as

in high school, when "he wouldn't eat" because of his

phobia of germs. "And it was so sad, so severe, that

we were thinking of taking him out of school, we

didn't know what to do."

Charlotte finally described the shattering

experience of receiving her five-year-old son's first

(and incorrect) diagnosis. The effect of this event

was tragic and added to the calamity of her

experience:

> And [the psychologist] called me on the phone
> and over the phone told me, and I'm standing in
> the kitchen, that's what I was doing…that [my
> son] was a paranoid schizophrenic. And he would
> probably have to be institutionalized by the
> time he was twelve. Well, I looked at him and
> he's like five years old. He has a sweet little
> face, you know, this cute little boy and I'm
> just going, What?! And I remember I had to pick
> [my husband] up, he had an eye appointment or
> something and, even that I would remember…we
> went to Oak Park so the boys could play before I
> picked [my husband] up. And I remember sitting
> in the grass just sobbing…thinking, Why did they
> tell me this on the phone? And how could they
> tell me this, why didn't they have me come in?
> Why didn't they tell me in person? This was so
> unbelievable.

Charlotte began her narrative of the ongoing

frustration of dealing with her second oldest child

with "My history with [my daughter]; Oh Lord have

mercy." This premiere statement defined the nature of

the struggle and distress with her offspring which

began in utero and has continued to the present day:

> My pregnancy was placenta previa, placental
> abruption. Which means that the placenta grows
> over the mouth of the cervix instead of up on
> the side of the womb like it is supposed to do.
> Throughout the pregnancy I had six hemorrhages.
> They did an emergency Caesarean and had to work
> on [my daughter] to get her breathing. She's
> always just been a very difficult child. When
> she was little she was sick a lot because…her
> lungs were not developed when she was born. She
> had pneumonia many, many, many times. When she
> was two, on her birthday, her father left.

Subsequent life events added to the early

trauma. "One time she ate 350 thyroid pills and an

unknown amount of tetracycline at somebody's house…"

Charlotte was often "just at my wits end." Her

daughter's behavior and explanations for the

motivation behind it remained a mystery; "…she drank

Ivory liquid, she ate glass…she seemed incapable of

telling the truth…and no matter what I did it didn't

make any difference."

The ongoing heartbreak of dealing with her

daughter into adulthood was marked by perceived

thoughtlessness, "She wasn't bad…in high school…she

wouldn't tell us where she was…and you're just

frantic"; wild stories, "Like she ran into John Travolta on State Street and he was complimenting her on how nice her skin looked"; and a failed marriage, "...we'd say to her...we see just a lot of red flags." A borderline personality disorder diagnosis with co-occurring depression ultimately explained much of what Charlotte had lived through over the years. But she expressed the discouragement of a parent overwhelmed by the enduring havoc of mental illness:

> I just can't even begin to tell you how frustrating it is to try and deal with her or help her. I pretty much have withdrawn. I just don't do anything with her, almost nothing at all. So [my husband] does just about everything with her because I had just reached the maximum frustration level. I just feel anger. Then I feel like I'm a really bad person because I can't muster up pity for my own child...she's such a drama queen, I just don't know...makes me so frustrated...I just want to shake her. I feel a lot of guilt...I just feel lost.

As Chris recounted the details of his childhood and adolescence, he talked about the emotional reaction to and impact of being raised by a parent suffering with a mental illness:

> So...growing up with a parent with OCD, junk collecting...hoarders is the word I was thinking of...it's like having a parent with alcoholism,

> but…all the neighbors can see and it affects
> them directly because there's property values
> and that sort of thing. I think if my dad was an
> alcoholic and he beat his kids and his wife,
> they wouldn't care as much, sadly. I was 15…I
> was actually at this guy's house and…the kid
> told me that people gave my dad stuff for free
> because they knew he would take it and it was
> their way of getting rid of junk…they were
> laughing at my dad, and it was shameful…at that
> moment, I became angry with my father and I
> hated him.

The unpredictability of such an environment is revealed in his beliefs about the world and self, and that influence on attaining goals: "…I'm having trouble being motivated…"; "I feel like my attention span is short…"; "I know I'm not normal…"; "I have a negative reaction towards someone who has their life in perfect order…" The loss, and what could have been, is evident in Chris's narrative: "…if I had a normal parent, or a healthy parent"; "I would have friends over but…knowing how to be hospitable, entertaining…I didn't."

Chris found a way of escaping from the clutter of his upbringing, "…graduated from college…left the house as soon as [I] could to get away from it all." But yearned for validation, "I felt I needed to be

something in order to impress the rest of my family"

and feared the legacy of his father, "Oh gosh, do I

have that, or will I get that?"

Even as an adult, the ignominy of his father's

illness shapes Chris's thought life, "…I just kind of

want to be invisible sometimes", and their

relationship:

> Occasionally, when my dad has come to town to
> help me with stuff, we'll work on a project
> together and he'll want to take home the
> garbage. And sometimes I won't let him and
> sometimes I will. When I don't let him…he acts
> like he's being abused or tormented, or denied a
> privilege…rarely do I go home—maybe once a year.

Debra would not talk about the embarrassing and

shameful effects of having a son with mental illness

for a long time. "The more knowledgeable I got about

mental illness, the more I talked about it…" His

unpredictability was especially frightening as he

"often acted out in major anger" and "becomes

irrational", and then sadly "started blaming me" for

the calamity of his life.

The ongoing sorrow and frustration she feels for

her adult son is evident in her narrative:

…a great deal of disappointment that he had such plans to do something and he never accomplished them. I just felt a great deal of sadness. He had big dreams and he never fulfilled them. He's a talented, gifted artist and [he] could've done something and I don't see any of that being fulfilled and I'm sad for him and, he's just all negative. He sees no future, no possibilities of anything when he had such dreams, and that was it…he just thinks of himself as a failure and I just am sad about that.

Debra's continuing concern is for her son's future—"I'm not sure how we're going to deal with it. If he lives longer than we do." She also bears the burden of his threats of self-harm, "He's always had this desire to kill himself" and poor self-care, "He thinks he's going to die soon. He's terrified and I know that because he doesn't take good care of himself."

Her son is currently living in her home and Debra is torn between duty and setting boundaries:

I get fearful thinking how we're letting him be so much a part of our life, that he's going to consume it—our lives. I'm sad that he never sought help. I would threaten to kick him out if he wouldn't get help. He'd leave and then not do anything about it and somehow he'd worm his self back into the house. So there's times I feel helpless…and he goes on and on and you just want to just go, 'I've had it. Don't want to talk about it. Just get out!'

Debra consequently feels manipulated—"He gets his way through his speech."

Dennis exhibited the ability to apply reason to the reality of having two children with mental illness and was mindful in his approach; "…our attempt to deal with the situation in the very practical sense is an attempt to do the right thing." His response to his children's eventual diagnoses was not "oh, how horrible" or "holy cow, we've got a mental case on our hands" but rather relief over receiving accurate information and the beginning of vital answers to assiduous questions. Yet the real life effects of mental illness were present nonetheless:

> …there is this impact…of uncertainty, or not knowing particularly what our daughter is going to say to somebody else, particularly either about us or who knows. We have had sufficiently extensive experiences where we have had to deal with something that she has said to somebody else that was either untrue or so dramatically misconstrued that…so there's this sense of uncertainty over potential embarrassment.

At the extreme, Dennis honestly admitted "the inclination is to just say, 'Shape up! Why are you behaving this way?'" in response to the frustration

and difficulty of managing a son <u>and</u> a daughter

suffering from an array of mental health issues. He

described dealing with his son's differences as "the

roller coaster ride." An obsession over things

religious, scrupulosity, in high school almost brought

his son's functioning to a halt. "It would take easily

three hours to eat dinner because he had to pray over

every bite." For his daughter, Dennis was sad that in

all likelihood she was "not capable of fulfilling our

expectations…our desires for her" and that she was

aware of this at some level.

In the end his most compelling concern was for

the future of his children and the uncertainty of what

might happen to them:

> I could retire at any time, [but] this daughter
> is just in a sense creating havoc…with our sort
> of empty nest, pre-retirement, anticipating
> retirement kind of thing; here we are just
> consumed with what to do about her… So all of
> this is taking a lot of our sort of emotional
> energy and time. She is 40-something years old,
> and she is a child who cannot cope. Whereas our
> son at the moment isn't really taking an
> inordinate amount of time other than the usual,
> when we see him on Sunday and we get together
> for lunch. We're saying to ourselves, O.K.,
> we're here and we can help and we can do

whatever we can and at least be around, but what happens when we're gone?

Helen was very clear about the force with which her son's first major break struck her. She articulated her experience in terms that brought very definite visual images to mind and expressed the profundity of this event in her life:

> I felt like someone had just banged a gong in my head… I said, "Oh my God!" I couldn't think at all…and went into high gear. Vah, vah, vah, vah, vah! …and it scared the hell out of me, and I had probably two of the worst years of my life until I saw that my son was going to be okay. I went through a period of being really frightened and just really restless and unable to relax. I was so focused on my son.

After surviving the initial impact of the verdict that her son had received, Helen began to reflect historically, wondering "Did I miss something?" and "Did I hurt him some way?" She felt so responsible when she remembered that "he said he had been manic before in high school", "he started telling me then that there was something wrong with him…he kept insisting." During an exercise in her master's program she mapped her family tree and began to recall the behaviors of family members:

> Oh my God, it's my family. This mentally ill grandfather and uncle who did bizarre things, and my own father who I always suspected…might have been bipolar…when you look at my family, it looks like it is, [genetic], you know? My father's side of the family…since I got my master's Degree in Clinical Psychology…I have uncovered more stories about cousins and second cousins that have this problem, this bipolar disorder. If you look at my family tree…I put a yellow dot for everybody that has a bipolar problem or some kind of odd behavior, and it looks like someone went *poom*! It's just scattered throughout. Oh my God, and all I could think of was my uncle and all the things he'd done with money…

The shock of this revelation in relation to her son was evident: "I was…so worried that my son would not make it through this because I was thinking of all the worst cases of illness." The stigma of her son's experience also became very personal and heartbreaking when he told her "'…people were afraid of me, Mom', and then he cried." Helen also began to fear that as a side effect to medication "[my son] is going to be talking funny and in an affected manner." Ultimately, the shame seemed unbearable: "that's all they want to do is just hide this…I felt terrible."

The first sentence of Jennifer's narrative defined the real life story of having a sister and a

nephew suffering from mental illness: "Well, it's changed the course of my life." Her experience was characterized by words and statements that emphasized the overwhelming nature of her experience:

> …it is so disruptive…it's so difficult…it's hard coping with it yikes! …it was too hard to deal with…all the anger…really disappointing…no easy answers…it tugs at your heart…it's not that easy to be objective.

Jennifer and her sister were very close, and as the eldest she felt responsible for her and "I just tried to be…the mediator in the family." Her parents appeared unable to respond to her sister's ongoing difficulties and emerging mental illness: "…in that time, there's not a lot of people that talked about problems." She admitted "I took a lot of drugs as a kid; I thought everybody was…using drugs." But then "I saw my sister…she sort of like went out of control."

> But see, my parents instead of dealing with well, you know, what is actually going on here, they just…all of it was about the drugs. But then there was not really trying to understand, or just only very briefly, Why is the drug use there? And so I think that they were so like, Oh my god, we're the only family that's got kids with these problems, and, you know, sort of like, let's not…or, they didn't want to really, it was too hard to deal with.

As an adult Jennifer took over the responsibility of raising her nephew because her sister was too ill: "And I wasn't a mother at the time." She became very emotional as she relived the scene: "…he was 4. You know, that was a big step right there." She began to see "in kindergarten things started" for her nephew. "Even with all the intervention" her nephew eventually took the same road as his mother, used drugs, got in trouble as an adolescent, and "right now…he is in prison". For Jennifer the inevitability of such a tragedy was hard: "…with him I was watching for it. Well you know it's a toss up; even if you do see it, it doesn't mean that it's going to be any different."

Marie's personal experience with mental illness, "I have been diagnosed with depression for over 20 years" provided her with some awareness of its complexities. However it was still "extremely challenging and at times frightening", particularly when her 14-year-old son "pulled a knife on me." This

event became "a defining moment"; it was an indication that something was fundamentally wrong:

> When [my son's] personality changed radically at age 10, I thought it was depression. When he complained to me in the 6th grade of people photographing him…I had no clue it was delusions. I got a letter from the…elementary school principal saying that there was a pedophile in the neighborhood. About age 14, [my son] had a complete breakdown…the psychiatrist who was treating him at the time here told me he would never come home again…

The worst time for Marie "was between the misdiagnosis of depression with psychotic episodes to schizophrenia." Even then, knowing what they were dealing with, still "it was a very, very negative diagnosis" and "I've had four psychiatrists tell me that it was the worse case of paranoid schizophrenia that they'd ever seen."

For Marie the experience with the psychiatric facilities and attending doctors added to the negative pall that had descended on her life:

> The mental hospitals were awful, awful, awful. They were no help. They didn't communicate. The doctors wouldn't call back…they're spending all this time charting, but they're not getting the medications right…and doctors who sometimes didn't believe [my son] was having hallucinations.

The impact of mental illness also completely altered the requirements of Marie's daily life—"He had more trouble at school than the other kids." She ultimately left her job and career to accommodate the needs of her son, "I'm literally on call 24/7." The fallout from this daily vigilance has "very honestly created problems in our marriage":

> My husband is extremely frustrated that when we go away, we have to take [my son] all the time and he can't look forward to a normal retirement.

Tom's youngest son began exhibiting behavioral symptoms when he was 10. Tom spoke about the experience of watching his son change before his eyes, and the shock and sadness of observing such a dramatic alteration:

> He was a good kid…it's very difficult. He went from an outgoing, affable, fairly loving child, who was quite characteristically…always very concerned. Very much the care-giver. And then that changed. He became sullen, withdrawn, quiet…we had some of our other older kids go through periods like that…but he didn't snap out of it. I mean recognizing your son has a serious, potentially catastrophic mental condition, is just a heck of a thing to deal with…it's very difficult.

Ultimately, seeing his son go through such an irreversible personality change wrought probably the most unthinkable personal changes Tom could have imagined; "Well, we kind of grew apart…incrementally."

Tom recalled the subsequent upheaval of finding the right treatment for his son—"…the whole drug therapy thing is a painful experience", "was a crap shoot", "medication that would maybe work and then they wouldn't." The numerous hospitalizations didn't always feel helpful and left him feeling dissatisfied with the outcome—"I mean, he came back worse than he went in behaviorally" and "you were kind of at their mercy" because of the lack of communication "between the hospitals and our doctors." A higher level of care was finally recommended for his son and "we had to commit him on his 16th birthday" to a facility in Reno, Nevada. "…the worst day. That was horrible."

Tom was honest about the effect of mental illness on families, particularly couples:

> …it's probably hell on marriages…because it's such a catastrophic illness…when we went on vacation, we had to either decide to take him or not go, or it was more difficult to do kinda

> weekends alone as a couple…our ability to be independent became less so…you gotta think two or three times about leaving him alone for periods of time.

Resources

Some families found support in the services of mental health professionals and agencies. Others were deeply grateful to teachers and schools for going the extra mile. Self-help went beyond cliché for a few seeking a mainstay of empowerment in themselves.

Many sought support in faith communities (churches, synagogues, etc.), family, or with people going through the same experience (NAMI or similar support groups).

Charlotte found that individuals, schools, and agencies played significant supportive roles in assisting her son and her family. The relief provided by these resources contributed to the long term ability to deal with an unremitting situation.

The teachers and administrative staff at the grammar and high schools were integral in her son achieving academic success and crucial socialization:

> However, he did have some good school
> experiences, at Random Elementary School…the
> teacher was just probably the best teacher I've
> ever encountered…she was just terrific. And she
> was so creative about how she enlisted the other
> kids to help him…she allowed him to stand at his
> desk instead of sit there…and when he went to
> Random High School, the same thing. The kids
> were just terrific, they really helped him a
> lot. The teachers helped him; it was just a very
> good experience.

Charlotte also enlisted mental health

professionals who provided timely intervention for her

son and "I called The Autism Society and they put us

in touch with [agency]" which supplied ancillary

services for her beleaguered family:

> …he did a lot of therapy with
> [psychologist]…that seemed to help.
> [Psychologist] gave him tools to kind of deal
> with [the OCD]…then we got hooked up with
> [agency]…they got us tons of help…about two
> years of occupational therapy… They gave us
> respite care funding, where they would have a
> professional baby sitter come and watch the
> kids…that was really, really nice.

As an adult, Chris sought groups that addressed

the issues of his childhood experience but could also

provide answers to his ongoing questions about his

experience with a parent who suffered from mental

illness:

> Well now there's websites for children of
> hoarders, there's actually a hoarding support
> group here in town that I go to from time to
> time…it's just a support group. It's free, but I
> do even go to a 12-step for, uh, addiction. And
> that is helpful, too.

Debra provided a concise account of how and where she found support. "When I was able to admit it" she simply "realized that there was help for me and support for me"; co-workers, good friends, and being in group [therapy]. "I've…learned to seek out help, to get support." A primary source of support was "being able to talk to my husband about it. I can commiserate with my husband and we can share with each other." These simple resources have continued to serve her well no matter how severe the circumstances.

Being a pragmatic person, Dennis used that practicality to find the means to deal with his family's situation—"We tried to figure out what to do. We went looking for resources." He actively sought the support to buoy up the ongoing challenge of two children with mental illness:

> …we have had a little bit of involvement with
> the local NAMI…for a particular class. A doctor
> down at UCLA who had had some experience with

autistic persons…he could give us some sense of what to expect [from our son]…for our daughter…we began to seek out what kinds of help we could get her…a psychologist here in town…gave her about a three hour battery of tests… So, in both cases our reaction, I guess, has been, O.K., what do we do now?

It was also important to Dennis to find a mental health professional who was sympathetic to the issue of his son's faith:

One element of that solution was that [son] spent some time with a Christian psychologist, and I emphasize Christian because the issue was his faith, was his relationship to God. And he was given some tools as a result of being with that psychologist.

Creating a support system for his daughter has required a bit more resourcefulness on Dennis's part:

With the daughter…trying to figure out what to do…somewhere in there we began to seek out what kinds of help we could get her. She doesn't have a very good history of staying with it. We are right now at the point of initiating some intervention, just the very, very, very earliest stages of that. Our first reaction is, O.K., what do we do now, and what's available to us and what are our resources, that sort of thing.

Helen didn't know about or access community support groups such as NAMI (National Alliance on Mental Illness) but felt that they could be helpful to families struggling with relatives who suffered from

mental illness. Instead "I went to therapy weekly",
something she was doing for her master's program but
which serendipitously met her immediate need.

Helen noted that one of the most important
things during this time was the university
psychiatrist who communicated directly with her during
her son's break, explained the treatment, and her
essential role in it:

> The psychiatrist got on the phone and said 'I
> don't want to hospitalize your son…and introduce
> him to that system.' He said 'I'm sedating him.
> He has friends that can help him right now, but
> you need to come up and get a motel room and
> take him there. This is the new philosophy…just
> knock him down…just knock this mania right out
> of his system by really sedating him.'

Her son's friends and girlfriend "who had
recognized what was wrong with him" were, by
extension, of invaluable help because they "caught him
at night; kept him from getting in his car" and got
him to the health center as soon as it opened.

Helen was clear that her religious upbringing
was a fixed source of aid, especially for the
unexpected and unexplainable:

I was raised as a Roman Catholic…it's really imbedded in me; whenever there was something serious in my family or at school, the first think you do is you say the rosary because that helps you handle the uncertainty and pass the time. I don't discount anybody's religion because it helps reconcile that which cannot be reconciled and it helps people handle uncertainty in a way that…without those tools, those actions and things, it would be very difficult for some people… I'm not a good Catholic at all but I'll never change…and that's what will come to me when I'm in distress.

Jennifer was succinct in her litany of what assisted her in confronting the challenges of familial mental illness, and what she believed would help others similarly challenged:

…family members become most of the resources. [At that time] you didn't see on Oprah these experts on all these different things. I was talking to the teachers, right when I saw [my nephew] had ADD, I got him tested, I had him at a child psychiatrist, he went to a therapist. Well, it's not just getting family therapy for sure…get somebody else involved if they can't. If it's at the doctor's office or the school or somewhere…getting other people to assist them that know what they're doing.

Two resource themes seemed to prevail in Marie's narrative: her church community and competent professional support:

I do remember relying a lot on [psychiatrist]. He was a big help. Don't use a therapist who has

less than a Ph.D. Get a good psychiatrist.
Coming to [the church] was a turning point. [The
minister] and his congregation were really
instrumental in getting me through this whole
time, so I've gotta say that. I hope it's okay
to talk about God in here, because I just want
to be honest. Okay. Real stuff.

Tom was grateful to the high school and its
response to his son's special needs—"Teacher was just
fabulous and so the school bent over backwards to help
us out. I have nothing but high regard for what they
did…he got his high school diploma." He was surprised
but thankful that "we were lucky with [our]
family…they were great, you know? …my brother-in-law
went up to Reno…to visit [my son] while he was in the
hospital."

The medical team was a critical part of the
positive outcome for their family—"I was happy with
our doctors, our psychiatrists. Find a good
psychiatrist." His wife was also a good record keeper
and "she pulled out a spreadsheet of his
medication…she had it wired. I had faith in [my wife]
as a care giver."

Tom's faith in God was often challenged while he was trying to find the right medication and the right treatment for his son. But his belief system stood the test of the circumstance and provided him with an unshakeable resource:

> …you have two choices. You know, you open two doors. You can open one, it's a denial of God and 'why is this happening to me' and 'there's no justice', 'there's no God in this world'…you open the door to God and you say, 'you know, I don't get it, but I still believe in God and a sovereign power, who has authority'. I think it really is just a free-will choice of whether God exists or not, and I choose that God exists and I'll figure out how all this makes sense at some point in the future, but it's not my call.

Knowledge

When Charlotte received the first diagnosis for her son, she decided she needed to educate herself about this disorder. Prior to this she thought he was just "an unusual little kid."

> So I went to the library and started to read about paranoid schizophrenia. And I read and read and read, and in the reading came across autism. And when I read about autism I go, This is what he has! This is who my child is! He fits perfectly.

After her son was correctly diagnosed with an autism spectrum disorder, Charlotte said that the next

hurdle was dealing with his OCD. A turning point was "discovering that scrupulosity definition…it seems like I was reading online". Charlotte's finding resulted in her son's therapist being able to address this religious obsession behaviorally.

When her son was fifteen, Charlotte said that they almost had to withdraw him from high school because "he went through this germ-a-phobic thing…he wouldn't eat."

> …in April I think, Prozac came out. And we found somebody in [City] who would be willing to prescribe it for him; we were going to try it. And gosh by May he was talking again, and he was thinking again, he was kind of like himself again. He took his finals and he did pretty well. That was a huge life-giver to him and he has been on some kind of drugs like that ever since.

For her daughter, a turning point for Charlotte was "getting the diagnosis."

> Well finally I was just at my wits end and I have a friend who's an MFCC…she said, 'Well I think she's a borderline personality disorder.' I read about it and I thought, 'Yes, she fits almost all of these categories.' We had the evaluation done…the result was that she has a borderline personality disorder. It suddenly did explain just years and years and years of frustrating behavior. It put them all into a place where we could understand. In a way that

was hard but it was good because it did explain a whole lot of what we had been through with her.

As Chris navigated the experience of being raised by an obsessive parent, he recalls when "I was eight…I don't think I really knew it was a mental illness. I just thought he was weird, you know?" This early awareness made him sensitive to other possibilities—"I just thought he was eclectic." It also contributed to a later and more mature understanding of a person's actions:

> …when they do something that they can't help, then there's an explanation and it kind of takes away the bite of the hurt. It doesn't take away the hurt, but it takes away the bite of the intention of the hurt, if there ever was one.

Debra emphasized the importance of putting her experience with her son into a manageable container— "The more knowledgeable I got about mental illness, the more I talked about it." She was relieved "to know that he really had that diagnosis and that he was getting treatment." Debra again stressed—"Get informed. Get knowledge." This concrete solution began to provide clarity for her experience.

Because Dennis is a teacher it was his normal tendency to seek information specific to the need; information that would answer vexing questions. "So it was…a matter of getting information and…the information was very vague at the beginning—it was all wrong."

> O.K., we knew something was wrong. The first major turning point was diagnosis and that didn't come easily. The initial diagnosis we got was horrendous…he was psychotic or schizoid or something like that. But when we read the description of Asperger's we said 'That's him'. He has never actually been formally diagnosed with Asperger's, we've just concluded that. He is high functioning autistic and has OCD.

Dennis was inclined to have a sensible response to and attitude about life, "I'm a relatively even-keel kind of person. I tend to take things pretty much in stride". Facts helped fill in the gaps—"I've gained knowledge about these diagnoses." Details elucidated the experience for Dennis—"…if we can get a better handle on what it is, there's a better chance of knowing what to do about it."

For Dennis and his family, the introduction of psychotropic medication when his son was in high school provided observable and life-altering changes:

> He was started with Prozac for the depression and also I guess for OCD, and it worked, it began to help. And he began to pull out of the depression and he just began to slowly function again. By the end of the school year he was pretty much back to whatever normal would be for him in terms of functioning.

Ultimately the impact of the mental illness his son suffers from has been mediated by understanding and knowledge—"The context and the reaction was more an enlightenment; we know what we've been experiencing." The experience with his daughter was somewhat similar for Dennis:

> It certainly was eye-opening to get the diagnosis and then read the DSM stuff. That was like, oh of course, that's what's been going on. My wife then looks back to her infancy and says, 'Yeah, all the way along I've seen some of these things, but just didn't know how to connect them.'

His daughter's diagnosis was a more recent development and he began "trying to figure out what to do." Sorting out the conflicting information Dennis encountered about personality disorders became his

present task—"The prevailing attitude is that there

isn't a whole lot you can do with a borderline

personality… Other people say, No, there's lots that

you can do."

For Helen, in order to help her son, education

was necessary and provided a way out of the

uncertainty of mental illness—"I'm going to do what I

have to do to make me understand; [the study of]

psychology just opened up that vista." The experience

of going through this journey with her son also

provided a personal awareness previously untapped:

> I learned a lot about myself and who I am and
> how I react and how other people see and think
> of me. Definitely. I think it helped me go on
> and realize what I wanted in my life, to be
> really self-reliant, to be capable and to not
> let things destroy me.

Helen believed that "information is power; get

information as soon as possible." From her experience

she learned and felt strongly about the efficacy of

medication—that the right treatment can have critical

effects on future functioning:

> Don't be afraid to use medications. Don't be
> afraid to let the doctors try different
> medication…those to me are tools. They're not

crutches. That's probably the number one thing that I learned is that people with these illnesses, especially with a bipolar disorder, need sedation. They need sedation before there's any damage done and my son learned that too.

Jennifer's personal experience of familial mental illness resulted in an awareness that "changed the course of my life" and "focused me into a different area of life." She also attempted "to learn more" in order "to help my relatives." This consciousness made her sensitive to changes in her nephew, "like in kindergarten things started." Because of her sister's illness "I was on alert." She pointed out the importance of "finding out" and "understanding earlier." Jennifer believed in the efficacy of education and the agency she works for has "an education committee where they're going to the schools and they're giving presentations" for the purpose of informing the next generation.

Defining moments that began to clarify for Marie the serious nature of her son's emerging illness, his "personality suddenly changing" and "the knife incident when I knew I was looking at something

absolutely beyond depression", also sent Marie on a

quest for information to explain her son's experience:

> Educate yourself about the
> physiological…physical component to mental
> illness. Every psychotic episode…does burn brain
> cells and these people need care…to take care of
> basic needs.

Marie believed that one of the strongest

mediating factors for serious mental illness was

"getting the right medication." She was adamant that

"medications for mental illness are not recreational

drugs." This was an important turning point. Another

turning point cited by Marie in this journey was the

"proper diagnosis", finding a name for what was

affecting their family:

> At least once we knew it was schizophrenia, we
> knew what we were looking at. You know,
> medication-wise and information-wise, and all of
> that.

Tom made a case for "early diagnosis" and its

"strong treatment implications." "The recognition that

it wasn't a behavioral issue", that "it was a mental

condition that required chemical intervention" was an

important revelation for his family but also for the

professionals providing treatment to his son. This was

especially imperative in finding the treatment with the greatest efficacy:

> I actually almost remember the day it happened. We were at a therapist's office and the therapist kept trying to push a solution that was kind of family-based—let's talk this through, let's get together—and I finally realized *that* wasn't the problem. You know, it wasn't the family, it wasn't [my son] in terms of what he was doing. It was some kind of other thing that needed a totally different approach.

Following on the heels of timely diagnosis and effective treatment, Tom stressed the enormous value of the right medication.

> My understanding is that…a drug regime can turn somebody who is extremely mentally ill and unable to deal with society, into a functional adult. If that can happen for [my son], it can happen for a lot of people, in my opinion, because he's got a real severe case.

Tom's son also came to his own realization that "Yeah, I need to take meds and when they help, it's a good thing." He also began "to communicate to us the symptoms that he was facing. That's helped out a lot." Tom felt that awareness from both sides of the issue—patient and family—made the difference for him.

Strategies

Some families found the strength to go on in the day-to-day mundane activities of life. Yet others found the ability to go on in the rituals of their belief system—The Rosary, daily prayers or weekly worship services—or caring for a pet.

Others established a plan of action in order to accomplish the simplest of daily tasks or goals with more stringent requirements.

Strategies included advocacy and service to others, making a difference, or a higher purpose. Some saw their purposeful action as outreach or a 'mission.'

Charlotte's strategy for dealing with two children with mental illness was often found in the ordinary:

> We just went on. Sort of putting one foot in front of the other. So that's the hard part of being a parent is getting the every day stuff done. We just muddled along. It was kind of day-by-day.

She also reached out to others who were interested in hearing her unique story and how she survived having an autistic son:

> I have actually talked to a lot of people over the years. People will find out that they have a grandson or their own child or their next door neighbor or something and they'll call me and we'll just talk. I can tell them how to get connected, how to network. I can do that. I've talked to people in different parts of the country. That's helpful.

Chris's plan for coping with the reality of a parent with mental illness was by "going to college, being independent." He discovered that he could "be my own person, be productive and be a good worker, pay my bills and be independent." As an adult Chris sometimes managed the history of and with his father "by sleeping, by eating, by becoming obsessed with cars, sex, fixating on girls." But "recently I kind of made a shift to speaking the truth and doing what's right…just because it's the right thing to do." Such a change assisted in moving Chris closer to a middle ground in plotting a course through his family experience.

Debra remembered the methods she used to manage the often violent and very difficult situations with her son. It was easier to "not to engage in his irrationality…we tried to just maintain." But if the situation was out of control and she felt threatened "we had him arrested." As a result of how hard this was for her, she found other ways to cope and only reverted to legal intervention as a last resort:

> To be able to stand up for what I think is right and to be able to listen to suggestions about what to do. I've been able to use the strategies that people have suggested and implement them. I've laid down very strong boundaries.

Overall "I just kept going" by "trying to do what was right as far as raising my children." Debra found respite in being away at work all day "and not being around my son", and solace in the habit of supplication—"I prayed."

Whether it was a deliberate strategy, Dennis chose to educate his son in mainstream classes—"He has never been in special education…he went to private school"—which resulted in successful completion and graduation. Dennis felt that another important goal

was for his son to learn to be on his own as far as he was able:

> Another major turning point is our decision for him to move out of our house. It has certainly been a turning point for him and in our relationship and experience with him, for him to be living out from under our roof and gaining some independent living skills.

Dennis acquired skills to manage his son's difficulties which involved "behavior modification…intense intervention…that occurred over a period of time." He admitted that "just coping with the situation was the focus of our lives and our attention" on a daily basis. Yet the intercession of ordinary routine was a potent tool:

> You learn to take one step at a time, one day at a time. No matter how tough you think your circumstances are, there are lots of people whose circumstances are much, much worse.

Similarly with his daughter "we were just kind of going through life trying to deal with a child who lied a lot and ate too much and was perhaps the messiest person on the planet", but in the end Dennis said that their priority was "doing the just more or less normal parenting thing with her."

When Helen was faced with her son's first break she decided, "I have to go to what's more important…do what I have to do." Then "I was able to cope with my son very well." Other approaches she utilized to manage the upheaval of her life were rituals and distractions:

> I would spend time in meditation, and I would pray to Saint Francis and ask him to intercede with God and to protect my son. I had a big dog. I brushed him every night and walked him and that was helpful to have him and he was a good reason to come home; as well as to get to my shrine to Saint Francis with my picture of [my son] and my votive candles and everything.

In order to make her son a priority Helen chose to support him through self-sacrifice—"I think I abandoned my pleasure reading. I stopped watching television. I stopped a lot of things because I spent my time talking to my son." She encouraged others to make a difference and "support mental health".

"I have chosen to deal with it." This decision affected Jennifer's "ability to just go through the ups and downs, without totally becoming unglued." With her nephew she intervened early and "was involved with the school", "making sure he did his homework."

>When he started getting in to trouble, then I was involved in that, with the probation, with the team of services, with the psychiatrist. I was involved as a team member in it.

Even with her nephew in prison "I'm still involved to some degree with whoever I can talk to in there." Jennifer was similarly occupied for her sister:

>I had been an advocate for her too. Making sure she got treatment. I went with her to see her psychiatrist. She lives next door to me. Both my parents died, so I'm the trustee for her. Whatever basically is needed to get some stability. I make sure her trust pays for art lessons, she takes yoga, she has a good psychologist.

"Now I'm dealing with other people." Jennifer's purpose in life was to "help other people, other families, to educate them and give them some perspective", to be an advocate who can affect change incrementally:

>There's always an opportunity. 'Each one, reach one, teach one, recruit one.' So that's sort of like the mission I am on. And I really think it's just as simple as that; it's one person at a time, everybody you meet.

Jennifer's exhortation to others was to "not turn their back on this thing."

Marie began to cultivate the habit of attending church and "showing up at meetings once a month or every six weeks." This purposeful activity was crucial for her long term mental and emotional well-being and "getting me through this whole time." Marie also did her part for her son, and ultimately for her own peace of mind, by voluntarily ending her career—"I'm always on call." This strategy had a mixed effect by creating "problems in our marriage" but she felt the needs of her son were and are paramount.

Tom had a built-in distraction to deal with his son's chronic illness—"I had it easier because I had work." Yet the necessity of useful coping tools was still obvious to him—"you need some real strong intervention." Stepwise approaches assisted in developing the means for effective management:

> We realized over time that we had to redirect our activities more towards recognizing [our son's] situation. We went through, 'Okay, we got the disease.' Now it's, 'You know you gotta take this medicine, or trouble.'

Process

Charlotte's ability to affect change in her reaction and response to her daughter was still difficult. She continued to process the frustration of having a daughter she perceived is unable to alter her behavior:

> I know she's depressed. By the skin of her teeth and the grace of God managed to somehow graduate [from college]. But she hasn't done anything since then. Because of [my son], learning about him when he was little, I feel more compassion.

Nonetheless, Charlotte was able to look with incredible honesty at herself and processed feelings that could be easily misunderstood and condemned:

> I can understand why people would kill their child. [My daughter]…she was so difficult. Not that I'm condoning it or anything but I'm a little sympathetic sometimes.

In his process, Chris focused on the impact of his experience on the practicalities of daily life— "Now I'm in a job where I'm working out of fear to keep going. So I'm working on all that stuff right now." In addition, his attention was on the future and his hopes for it:

> I'm looking for a mate and my self value is
> linked with where I came from and where I came
> from was a garbage dump, so I feel like garbage.
> I don't feel good enough for the kind of person
> or the ideal mate that I have in my mind.

Debra's years as a therapist were evident in how she described her ability to manage years of ambiguity with her son—"It's just been a process." Because of this history she was able to look at the reality of her son's life and allow him to make his own choices in spite of her efforts to intervene:

> We tried to get him help; he refused. He is
> going through bankruptcy, losing his home. He
> has claimed that he was losing his home for four
> or five years so it was…hard to believe if that
> was happening. But in reality, he really is. He
> threatened to 'go out in glory' is what his
> words were. It was good for him to get angry,
> but he was scary.

Dennis typically approached the reality of his two children with enviable equability:

> It would almost be easier if these people were
> more [obviously] severely disabled. The stigma
> of mental illness [therefore] isn't prominent in
> my experience. It seems strange to hear myself
> say 'dealing with a mentally ill person in your
> family,' because I really don't attach that
> label to my kids.

Helen demonstrated a very succinct attitude about and response to the huge life shift of dealing

with her son's first break in college: "Well, it

changed my life. It made me come to school and get a

master's degree in clinical psychology."

Finding functionality was about constant process

for Jennifer. She approached this challenge daily with

the rejoinder that "it was a choice forced on me in a

way." But she moved on to the internal dialogue that

defined her narrative:

> I realized that I thought I could have more
> influence in getting my family member to seek
> help. But see, then that's about me you know. I
> struggle with that on a daily basis to want to
> get in there and try to control. Then it's,
> 'Wait a minute, didn't I just have this
> conversation with myself, that I could not do
> this.' [It] is a constant adjustment. No easy
> answers.

Marie was forthright in sharing her story. She

did not appreciate receiving unsolicited advice and

found the fear and ignorance of mental illness

difficult to bear. Yet she continued to process the

exasperating effects of having a son suffering from

mental illness:

> People will do anything they can to distance
> themselves from your situation so that it won't
> happen to them. There's a lot of fear…every time
> I hear of some crime or some car accident

they'll say, 'Oh well, they had antidepressant in their system'; that's always associated with the cause.

Tom exhibited the willingness in his process to look forward to the inevitability of what his life would be—"The biggest impact was loss of independence from the child as he grew older." In addition to what it was at the most difficult of times—"He came back worse than he went in behaviorally." Tom showed immense generosity to his wife who "had a much harder time…you know, 24/7."

Coming to Terms

Charlotte's story kept coming back to how difficult it was for her to have two children with mental illness but as she came to terms with the chronic challenge these children presented, she found some resolution, particularly with her son:

> There was a lot of pain at the beginning. Those early years were hard. But he surely is a whole lot better than he was. But now he's an interesting person and he makes my life interesting. He's fun, he's got a great sense of humor, he's a walking encyclopedia, you can ask him anything and he knows the answer. Maybe this is good to remember all the agony of getting that kid through the various things of life.

Charlotte still struggled with her daughter and the ongoing frustration—"I am so tired of waiting." But "we're getting her some help now". She admitted "we have very little control" and finally confronted this unyielding situation practically in one area— "I've always done all of [my son's] banking and now [my husband] does all of hers." What seemed to help Charlotte move on was the realization that "we're all on the same journey." This insight appeared to provide an anchor in a still uncertain arena and hopefully continued to serve her on her own journey.

Chris admitted that the experience of his childhood and where he came from made him shy "because it's shameful." Nonetheless he learned to appreciate how hard it was and is for his father, as well as valuing the positive qualities in this parent. He was also able to convey a feeling of love for his father and put into clear language who he was in relationship to this individual; and then step away:

> There's a lot of people out there like that
> [hoarders], so they're not the only one.
> Hopefully, people's faults or people's illnesses
> gives siblings or families or loved ones, the

insight to love other people with similar or any difference. He has worked hard all his life to put his kids through college; that's one really good thing he's done. One of the points while at college was realizing I needed to love my parents for who they were, including my dad.

Coming to terms with the past has brought Chris full circle in many ways. He had the choice as to how he ordered and controlled his environment—"At my own house I can throw stuff away and clear stuff out." Despite expressing the shame and humiliation of where and with whom he grew up, he was able to articulate feeling "clean" at times. He also felt he had some control over his life—"I'm living on my own, doing my own thing, being master of my domain."

Chris emphasized the importance of having an attitude of acceptance, viewing people from an inclusive perspective that avoided judging someone on the basis of external characteristics and behaviors. He was able to internalize important lessons learned from his experience—and from his father:

I think it has made me more thoughtful and more introspective about problems that people have. Somebody else's junk is not you, does not define you. I think for me and for my parents, they don't always look at people from the outside and

make a quick judgment. That person is loveable
for who they are and that [you] should try to
love that person.

In the end his father set the ultimate example
for how Chris lived his life—"When my dad dies I would
say at his funeral; I would say that he was a nice guy
and he treated people right."

Debra identified appreciation for and gratitude
to her son as a salient factor on her road to
acceptance:

I appreciate what he does do that's positive,
which is a lot. I compliment him. He is
extraordinarily helpful around the house. He's
got the yard looking wonderful. He's done some
definite good works improving the house. What we
give him, he gives back. It's comforting to my
husband to have someone around because of his
ill health.

Being able to see the redeeming value in her
son's acts and intention helped Debra step back and
see what she had learned in the midst of the chaos:

I've definitely grown stronger, learned to seek
out help, to get support. I didn't have to fear,
feel so shameful; there was just less criticism
than I thought. Not to take it all personally.

Dennis was able to find comfort in
intellectualizing the experience, which did not imply

that he did not react to the situation emotionally. He was simply able to look pragmatically at what was happening and find a cognitive compartment in which to place the event. This equanimity appeared to serve him well in responding to a situation that might have proven more daunting to someone else:

> With [my son], because his difference was evident much earlier, it's become in a sense a way of life. In life up to that point and since that point, there have of course been the sort of peaks and valleys of dealing…but many other times when it is a relatively normal existence.

He described the experience of having two children with mental illness as "disconcerting" and "frustrating" but then moved on to an explanation of those words and his response to them, either externally or internally.

> Life is what you do with what you've been given…the hand that you've been dealt. I've been dealt a pretty good hand and [my daughter] has been dealt a pretty crappy hand. She has a very difficult relationship with her mother. I feel like it's part of my responsibility…to try to deal with [my daughter].

The means by which Dennis confronted and dealt with his situation "is my personal faith" and "the belief that you are dealt your hand by God."

> We are a family of faith and that makes a
> difference. I think it makes a difference in our
> commitment to family. I have this pretty strong
> commitment to trying to do right by family. In
> the grand scheme of things and the purpose of
> our lives, part of the purpose of our lives is
> to do the right thing by these kids, by our
> kids. The overall purpose of the meaning of my
> life is to do what God calls me to do. And one
> of the things God has called me to do is do the
> right thing by a couple of mentally ill kids.

Helen's ability to come to terms with her son's illness was bolstered by early intervention and treatment, and receiving accurate information. The combination contributed to her sense that "I will be very well-equipped to understand what's happening" if the need ever arose again. The immediate response by a knowledgeable and competent doctor may have made the difference between success and a lifetime of hospitalizations for Helen's son—"He graduated from the university with honors and his psychiatrist told me, 'My patients who are students, they drift off and they never finish.'"

Connecting with her son during his first break also created an important conduit of communication that played an important role in his ongoing

stability. Helen "got an insight into his soul and now we have a bond that I don't think will ever be broken."

> I don't worry about my son anymore. He had a couple more manias that were sedated. But now he's been stable for a long time. I check in with him from time to time. Occasionally when he gets really upset I invite him out and I spend time with him. Now I only have fleeting concerns when he's under stress. Otherwise, I've gone on with my life.

Helen willingly admitted that "it has taken me years to find some kind of balance." Confronting the illnesses of both her sister and nephew "has taken a lot of work." Yet she was "able to find my own life…in the midst of it." She also admitted that "you can't change it; but I thought I could have more influence."

> [My nephew} is in prison. Even with all the intervention there, it could not stop that part of it. It's just that you cannot control another person. That is not my role to play in this, and it's going to have to be as good as it gets. I advocate for them, if they want help, but then that's all I can do. Not take it so personally.

Jennifer demonstrated in her narrative that her acceptance of and moving on from familial mental illness and the distress of the families she served in her agency "is a fine line" and "just a constant

adjustment" between being able "to let go" and trying

"to control."

> It's like, wait a minute; didn't I just have
> this conversation with myself that I could not
> do this? And so I struggle with that on a daily
> basis. I have to turn around and be able to say,
> O.K., this is just the hand dealt in life. What
> can I realistically do? This is my daily talking
> to myself. So I have a lot of practice, I get to
> do this every single day of my life.

Marie was insistent about the importance of

early diagnosis, treatment, and the right meds, along

with receiving competent services and support from the

various mental health professionals in her coming to

terms. However, in all that she had learned,

experienced, and become in this process Marie came to

the realization that "I'd trade it for [my son] being

normal." In the end her faith brought her to this

understanding and stood her in good stead through the

turmoil of the past eleven years and into the future—

"I have no hope without Christ."

Tom spoke about acceptance as a significant

factor in the process of coming to terms with his

son's illness. "I just accept it for what it is. I

don't really think we could have done anything about

it frankly." Tom mentioned that it was easier for him
to accept that his son was better when he came home
from hospitalizations and that that assisted him in
dealing with the situation:

> When he came home from the hospital, I accepted
> almost right away that he was better. Unless I
> saw a problem…I didn't believe there was a
> problem. I don't know if that's a combination of
> denial or just seeing a glass that's half empty
> or being an optimist on it or defense mechanism.
> Probably all of the above.

Tom's son "finally recognized the disease and
kind of has accepted it." This insight vicariously
aided Tom in his own journey toward acceptance and
meaning. Furthermore, celebrating milestones proved to
be the impetus for continued forward movement for Tom—
"We had a party that [my son] hadn't been hospitalized
in a year…we had a little celebration."

Model of Meaning for Family Members Who Have Relatives with Mental Illness

A careful consideration of study findings has
resulted in the development of a preliminary
conceptual model of the ways in which family members
with relatives suffering from mental illness make

meaning of their experience. The findings of the study reinforce the notion that family members with relatives who suffer from mental illness make meaning from their emotional understanding, the accessing of resources, the erudition of knowledge, the development of strategies, acting to bring about change, and struggling with and learning from the past.

CHAPTER VI: DISCUSSION

Introduction

Three men and 5 women described their lived experience with a family member suffering from mental illness from a variety of perspectives in response to open-ended questions posed by Researcher. The resulting themes were organized and categorized into levels or stages of experience that became the structural equivalent of the journey undertaken by these individuals in their search for meaning. These themes were characterized by the need for the experiential (feelings), the need to reach out to others (personal contact), the need for cognitive process (faculty of knowing), the need for an end purpose (a plan or objective), the need for an outcome (a consequence of action), and the need for an ultimate resolution from which meaning is derived.

The discussion of findings begins with an overview and contextualization of study findings from the narratives of the 8 participants. As additional findings of the current study are presented, they will

be linked to existing literature in relevant fields of inquiry, including family adaptation and adjustment to threatening events, coping with life crises, and concepts of meaning. The discussion will then briefly address implications of the findings for theory, practice, and research, including recommendations for further research. The experience of the Researcher will be presented. Limitations of the study and concluding comments will close the discussion.

Overview of Findings

When the emergent themes from interviews were analyzed the Researcher organized them into six overarching categories. These categories comprised a model or paradigm of meaning, the succinct concepts of which were: Emotion, Resources, Knowledge, Strategies, Process, and Coming to Terms. Figure 1 displays the model that provides the structure for my theory which defines the search for meaning. The six stages represent the discreet steps traversed in this personal journey. Emotions, or *affect,* signify the very difficult feelings and sentiment encountered at

MODEL OF MEANING

EMOTIONS	*Affect*
↓	
RESOURCES	*Access*
↓	
KNOWLEDGE	*Acquire*
↓	
STRATEGIES	*Action*
↓	
PROCESS	*Accommodate*
↓	
COMING TO TERMS	*Accept*
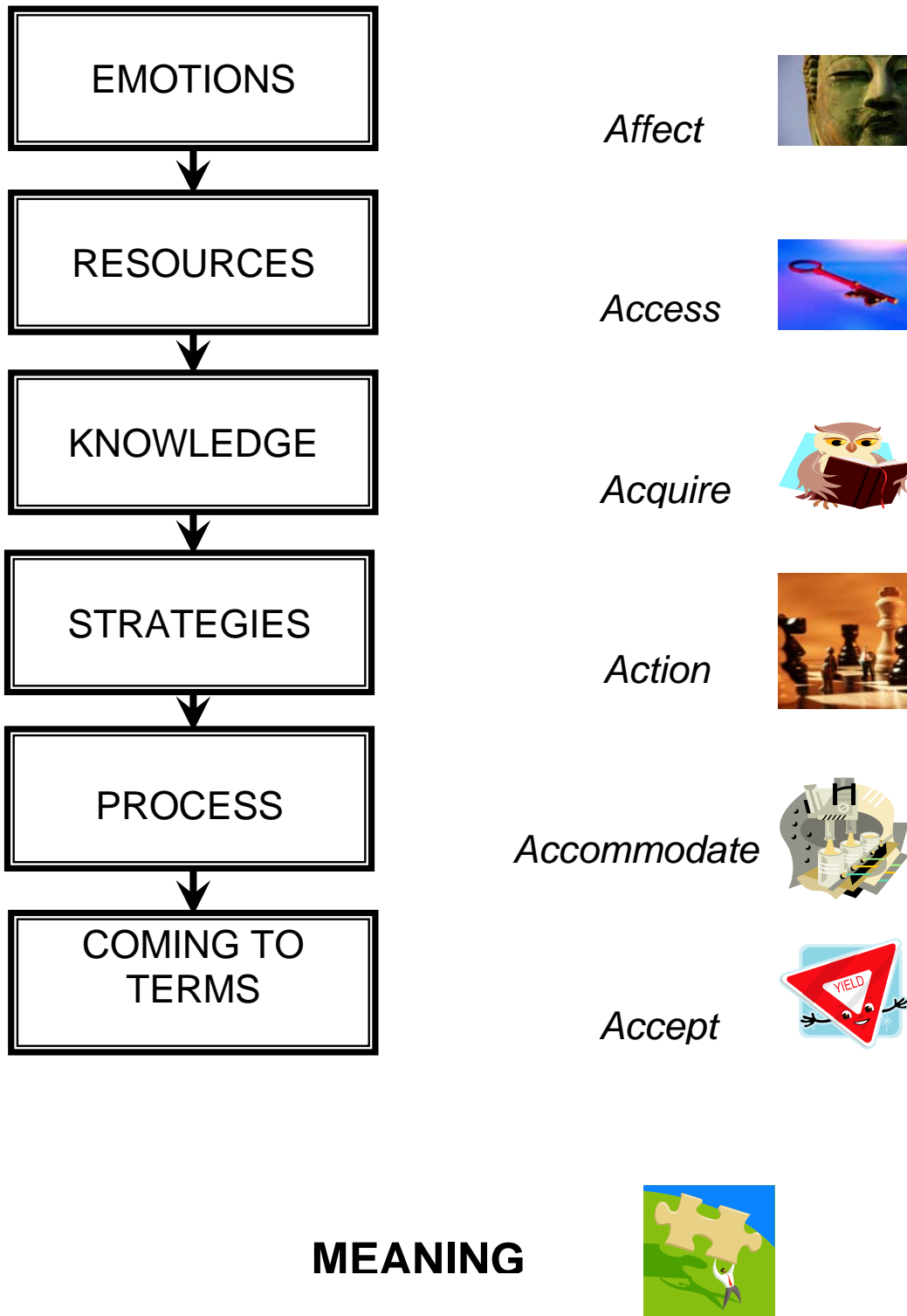
MEANING

Figure 1: Model of Meaning in Families with Relatives Suffering from Mental Illness

the outset of the experience. Resources, or *access*,
correspond to an available supply or support that one
need only retrieve. Knowledge, or *acquire*, is the
useful information that can be obtained through
diligent effort. Strategies, or *action*, are a dynamic
plan for accomplishing the next step. Process, or
accommodate, characterizes the method by which
adjustment is made to a new state. Coming to terms, or
accept, symbolizes an historical struggle and the
ultimate recognition and belief in the possibility of
a transformed reality.

Participants articulated a variety of
experiences and perspectives related to living with a
relative who suffers from mental illness. These
included narratives related to the disastrous and
unexpected nature of mental illness, the journey
through insanity to normalcy, the attending stigma,
accomplishments, and epiphanies, and the struggle to
make sense out of incongruity.

The narratives illuminated the importance of
community and family as well as the individual's ways

of being in the world often professed through expressions of faith and spirituality. Many participants expressed the existence of a personal belief system that helped them navigate through their experience. Those who referred to God, faith or spirituality emphasized the importance of having this crucial source of support and strength in their lives. Helen said specifically about her religious beliefs and rituals that "it helps reconcile that which cannot be reconciled and it helps people handle uncertainty." The presence of God or a higher omnipotent power, being part of an organized religion or religious group (a congregation or denomination, i.e. Roman Catholicism), the practicing of specific rituals (meditation, The Rosary, prayers, lighting of candles, shrines) provided affirmation that this all-powerful God or celestial presence had a higher purpose for experiences, events, and circumstances and would mediate the chaos and catastrophe of their lives. This belief of something beyond them appeared to help move the participants in my study beyond their experience.

The composition of study participants did not challenge any cultural or racial norms but represented the recruited and available population of families with relatives suffering from mental illness in the environs of a small American city. Seven of eight participants described themselves as Caucasian and one participant defined himself as Asian-American. Even so, what was important in their described journeys seemed to have more to do with what existed at the fundamental level of their humanity rather than in gender, tribe, or nationality. This 'impartiality of experience' in my participants' stories was only a tentative yet interesting observation and would require a more diverse cohort of participants for further validation. However, the suggestion that the human element is possibly more important than race and culture in this context was worthy of note.

The narratives illuminated how family members moved from Point A to Point B as they navigated the tenuous waters of mental illness. They clarified how families managed to find a safe and sane place to

function when faced with a mother, brother, son or daughter suffering with a mental illness. It is my belief from my research that there is a progression through certain somewhat predictive stages that begins with 'emotion' (affective reaction) and ends with 'coming to terms' (acceptance) and ultimately meaning. This progression involves change and responsive processing to the state until a trait is achieved or is being achieved. These stages are realized as the family member moves consistently forward through them. It is my hypothesis that each stage is attained before the next one is engaged; however it is possible and maybe even necessary that stages are revisited over time as new crises or events are experienced.

A preliminary theoretical model of meaning in families with members suffering from mental illness emerged from this study. It is characterized by the force of action, the tracking down of natural elements necessary for quantifying and qualifying indefinable experience. The structure of the paradigm or theory of meaning represents the experiential journey that an

individual embarks upon when faced with the reality of a loved one's suffering. Family members living with a relative diagnosed with a serious mental illness demonstrated the acquisition of meaning by the progression through specific stages of my model. These stages described above can be coalesced into the succinct concept of meaning.

Emotions-Affect

Defined as a strong feeling, an emotional state or disposition, especially expressed physically as in affect (Pickett, et al., 2001). Emotions are the primary response of human beings to their internal states and to the environment. Negative and positive emotions serve a "direction-finding" (Sudakov, 1997, p. 106) purpose and provide the means for expression of feelings toward other people or about the situation in which individuals find themselves. "Emotions usually precede overt acts or actions" (p. 106). Negative emotions in particular provide a source of internal energy. As they become more intense, the individual is mobilized, and becomes motivated toward

resourcefulness in achieving significant social and biologic results for overcoming obstacles (Sudakov).

When we experience something unexpected, frightening or traumatic, the protective factor of emotions can intervene and point us in the right direction. As feelings were managed, the family members' response to a relative with mental illness worked as a compass directing them toward a course of action that began to mediate the negative internal state or the situation in which they found themselves.

I found that the individual's initial reaction to the observation, awareness, or concrete identification of familial mental illness occurred in the realm of emotions and affect. These feelings were intrinsically interwoven and related to the response to and impact of such an event, of which these elements were the inevitable outgrowth. Feelings such as sadness, shock, or anger created or resulted in a response of helplessness, exasperation, desperation, denial or withdrawal, and impacted the individual (and family) with catastrophic, unexpected, and humiliating

force. Another response observed was conjecture about the possibility of different courses of action to this event; whether to be active or passive, whether to seek health (well-being) rather than normalcy (a sometimes indefinable construct), resulting in the emergence of a more positive effect by way of a person becoming more self-reliant, capable, equipped, and/or motivated.

Resources–Access

Defined as a source of support or help, an available supply; to obtain; or the ability to deal with or make use of a situation effectively (Pickett, et al., 2001). From the emotional, responsive and impactful realm, the next stage accessed in the search for meaning was making use of resources. This stage represented the family member reaching out to others to gain assistance and support in order to deal with his or her situation. Finding support and resources is a crucial aspect of the family's progression toward meaning. Resources could be readily available and came in the form of moral and community support, medical

and psychiatric assistance and cooperation, faith communities and belief systems (churches, God), as well as a sense of common purpose (teamwork). As family members transitioned from the internal stage of emotions to the external stage of resources they began to establish a foundation on which would be laid the product of their future efforts.

"According to crisis theory, an individual is especially receptive to outside influence in a time of flux" (Moos & Schaefer, 1986, p. 23). Emotional and material support from formal and informal sources plays a critical role in the facilitation of families adapting to stress (Unger & Powell, 1980). Families find strength to face hardship in the presence of protective elements and "the community has been a major source of social support for families in crisis situations" (McCubbin & Boss, 1980, p. 429).

Some found support in 'the system'; the mental health professionals or agencies who stepped in at significant moments to provide needed services. These services often afforded families essential respite

from the overwhelming and seemingly unending care-giving. Finding cooperation in others, particularly the professionals (doctors, therapists) was very germane to some individuals making sense of a catastrophe. Aligning with these service providers created not only a source of information but also an advocate for the needs of the family and the person suffering with mental illness.

<div align="center">*Knowledge-Acquire*</div>

Defined as the state or fact of knowing; familiarity, awareness or understanding gained through experience or effortful study; the sum of what has been perceived, discovered, or taught (Pickett, et al., 2001). Family members play a significant role in the lives of their relatives with mental illness. They are eager for and seek information about mental illness, its treatment and other relevant facts (Dixon, et al., 2004). Matheny, Aycock, Pugh, Curlette, and Silva Canella (1986) listed *seeking information* in their taxonomy of coping. "This behavior is aimed at gaining additional information

regarding stressors in order to reduce their

stressfulness and/or to improve one's response to

them" (p. 513). From resources the family member moved

on to the informational realm, an internal state or

condition. Once they were able to establish an under

girding philosophy and temporal support, the next

stage was the acquisition of knowledge. As the family

member was able to clarify and normalize his or her

experience, the state or fact of knowing provided a

container for what was uncertain and incongruent.

Information was vitally important for the

family; finding an explanation, an answer for

themselves and their relative in the midst of

unyielding uncertainty and chaos. The sources of

information were often found through education or a

diagnosis. Sometimes it was found in a definition or a

name for something previously unknown. Being provided

with a solution or finding a solution for the context

in which families were living also emerged through

medication and treatment. Psychotropic medication

afforded relief not only to the relative with mental

illness but to that person's caretakers. It often resulted in improved and more 'normal' functioning for the suffering individual often after years of anguish for the family. Sometimes knowledge came through lived experience or study, acquiring personal awareness, going through the ubiquitous epiphany, or through discovery.

Cognition is the mental process of knowing. It is an active process. Acquiring knowledge requires action, which is the state, condition or being of a process itself. One must become or enter into that which 'is' in order to know.

Strategies–Action

Defined as a plan of action, a series of movements; a plan being a detailed scheme or method for the accomplishment of an objective (Pickett, et al., 2001). When families are faced with events and circumstances that challenge their well-being, their more routine habits of functioning become inadequate. More resourceful and imaginative effort is necessary for managing such challenges. The resulting strategies

have endless variety and can return family functioning to its familiar routine (Reiss & Oliveri, 1980). From the cognitive realm the family member moved on to methods or tactics. After accessing the knowledge or information for moving into this stage, the family member began to develop a method, a form, an outline for functioning. Strategies may have presented simply as day-to-day routine, as obviously as coping and managing, or with more complexity such as in an individual's declared mission, outreach, or advocacy.

Strategies were active agency not passive and required thought and intention in their formulation. Plans had an objective or goal, the means for reaching such necessitated a systematic and detailed design for carrying out the proposed idea. Overall there was a purpose.

Process–Accommodate

Defined as a series of actions, changes or functions bringing about a result; to hold, to settle with comfortably (Pickett, et al., 2001). Undertaking personal growth and change is possibly the most

difficult undertaking of any human being. Expectations of the ultimate outcome of change and taking personal responsibility for such transformation may predict the ability to successfully process one's experience (Delsignore, Carraro, Mathier, Znoj, & Schnyder, 2008). The ability to satisfy basic psychological needs and attain valued outcomes is an effect of goal pursuit and attainment (Deci & Ryan, 2000). "According to the self-determination theory (Deci & Ryan, 1985), individuals striving towards a goal based on intrinsic motivation are more independent from external contingencies" (Delsignore, et al., p. 290). Achieving goals is also more likely when the determination is inherent (Delsignore, et al.).

The family member moved forward from planning to processing, the ultimate outcome of which was a result brought about by change. The process stage flushed out change; change of focus, change of perception, change of purpose, life shifts. Involved in such a transformation was exchanging one thing for another, changing position, direction, or place; function for

lack of function, insight for that which was indiscernible, a sense of purpose for that which was indeterminate or imprecise. The presence of chaos evolved to that of order; the place where the individuals found themselves had been transformed. The nature or condition of living with familial mental illness was no longer what it was or is. The successive nature of process moved the individual forward to the final stage of the search for meaning.

Coming to Terms-Accept

The idiom *coming to terms* comes from or is a composite of the German word *vergangenheitsbewältigung*, which "describes the process of dealing with the past"; a better translation in English might be the "struggle to come to terms with the past." (electronic source) The past implies history or what has come before. The quality of the German word is characterized in part by learning from the past. This concept embodies action or is an example of active pursuit. The search for meaning is a dynamic quest and requires persistence.

It also requires acceptance and the willingness to receive what was found. It is my premise that individuals might become stuck or entrenched at any stage short of arriving at meaning, not unlike developmental stages where one could be destined to squander time and effort in useless circular motion.

One of the coping skills posited by Moos and Schaefer (1986) is *resigned acceptance;* the decision that the "basic circumstances cannot be altered and submitting to a 'certain' fate" (p. 19). This attitude does not exclude seeking solutions in response to a crisis but assists in accepting or coming to terms with a situation when it occurs.

Coming to terms also involved the notion of a termination or an end. A *term* could be a specific period of time as in gestation or a deadline. But it could also refer to a meaning; something significant, something with intention <u>and</u> an end. This final stage was a culmination, an end to a search, an exploration for meaning which was an end in itself.

Current Findings, Existing Literature, and Theoretical

Formulations

The current findings confirmed assertions made

by other researchers about the nature and impact of

mental illness as disastrous (Terkelsen, 1987),

burdensome (Ferriter & Huband, 2003), and inescapable

(Marsh & Lefley, 1996). Family responsibility for the

current and future welfare of its relatives, and worry

about who would care for them when they were gone was

also borne out in the narratives (Muesser & Gingerich,

2006). Guilt and self-blame for what they might have

passed on genetically to their children was expressed

by most parents in this study (Ferriter & Huband,

2003). The single representative for children of

parents with mental illness provided evidence in his

narrative of the enduring effects of his experience

and its impact on his professional life (Aldridge,

2006). All family members experienced the burden of

being the primary caretakers of their relatives

whether children, siblings, or parents and the

incidence of this phenomenon permeated the narratives (Ferriter & Huband, 2003; Johnson, 1990).

The amount of time elapsed in the experience of familial mental illness (either from diagnosis or from the first observed evidence or awareness of symptoms to present) was not necessarily a contributing factor in the participant's facility for dealing with the experience. The longest period of time elapsed was 42 years and the shortest was 8 years. Individuals with a longer duration of experience didn't necessarily gain an advantage in the ability to cope or come to terms, over those who had not lived as long with a relative suffering from mental illness. Age of participant family member also did not appear to play a significant role. The youngest participant had lived with his father who suffered from mental illness for his entire life and expressed much the same experience and methods for coping as the older participants.

Relationship of the participant to the relative with mental illness did not appear to impact the results of this study. The dynamics in the

relationship however, may have been altered; such as the role one plays (parent to child, child to parent, sibling to sibling, etc.), the sense of responsibility which emerged in the concept of *temporal uncertainty* (parent for child), and gender to a small extent (females may have exhibited greater competence in dealing with the emotional aspect of their experience). However, whether one was the son, mother, sibling, or aunt, the path of experience remained the same.

The notion of shame emerged as a factor in the experience expressed by study participants. Examples of participant's experiences were the stigma and humiliation of having a relative with mental illness, and participating in self-deprecating attitudes and behavior. The concept of personal accountability, that somehow their genetics were substandard because of their contribution to the son or daughter with mental illness, was featured in the narratives of parents. Examples of these responses were represented by feelings of personal fault or culpability, feelings of

inferiority due to inheritability or flawed genetics,
feelings of pain, guilt or embarrassment for the
imperfect product they as parents created, and
overcompensation for what 'could have been' for their
child if different choices were made or actions taken.

The primary focus with regard to meaning-making
in this study was on the search, the process by which
individuals in families found meaning in the lived
experience of day-to-day life across the history of
their relative suffering with mental illness. Atkinson
(1986) writes "not infrequently there is a 'search
after meaning' as relatives try to understand why this
should have happened to their family" (p. 101). In a
theory of cognitive adaptation, Taylor (1983) proposes
that in the context of a threatening event, an
individual begins to adjust around three themes one of
which is the search for meaning. Similarly,
individuals in this study questioned the 'why' and
'what' of their experience.

Meaning is an effort to understand the event,
find significance in the event, and attribute cause

(Taylor, 1983). In the work by Thompson and Janigian (1988, p. 260), "a conceptual framework is presented for understanding what is meant by 'finding meaning.'" Their focus was on *found meaning* which they equated to the search for meaningfulness and understanding. They also examined the role of causal attributions in the search for meaning. This study has brought to light the idea that a search for meaning is initiated in the presence of a major traumatic event wherein contributory factors may be identified to explain the resulting distress.

Pettie and Triolo contend that individuals struggling through the process of psychiatric rehabilitation create or realize *chosen meanings* for themselves. Chosen meanings provide personal significance for the individual and serve to explain, understand, and interpret his or her experience. Life might not otherwise contain enough sense to eliminate the possible confusion of events and responses (1999).

Addressing the question of whether or not the search for and finding of meaning for families with

members who are suffering from mental illness results in their ability to come to terms with such an event certainly requires further discussion. However, most participants in this study demonstrated the ability to find acceptance in their experience. Therefore the findings of this study indicate that the presence of the search for meaning is a crucial element in coming to terms with familial mental illness.

Implications of Findings

Theory

The development of my theory of the search for meaning has been based in and derived from grounded theory, the premise of which is the emergence of theory from the data. Not unlike the work of Piaget and Kübler-Ross, both of whom were qualitative researchers and whose theories came out of the populations they studied (Piaget's daughters and Kübler-Ross's patients and their loved ones), the family members I interviewed provided a rich tapestry of experience that lead to my hypothesis of a model of meaning.

Although Piaget and Kübler-Ross were primarily published in book form and not subjected to the rigor of peer review, their findings were indisputably groundbreaking and continue to influence and impact the field (Morse, 2008). Lay persons and professionals alike are persuaded by the importance of their discoveries, and their scholarship and expertise are not dismissed. Kübler-Ross wrote of her book that "it is not meant to be a textbook on how to manage dying patients, nor is it intended as a complete study of the psychology of dying" (1969, p. 11). Instead it was intended for presenting the stories of human beings from which much could be learned about the finality of an experience common to all persons (Kübler-Ross).

Following in the footsteps of Kübler-Ross, as a qualitative researcher it was my intention in this study to discover a construct that might explain the experience of the families I interviewed. The ultimate outcome was to serve the families who act as the long term caregivers of their relatives with mental illness and to "learn much about the functioning of the human

mind" (Kübler-Ross, 1969, p. 12). This goal is not dissimilar to Kübler-Ross's purpose in exploring death and dying. The potential of the gathered data formed the results and drove the theory that evolved. The stage model of meaning that I found in my study is similar to Kübler-Ross's stages of grief model, in that it provides a starting point for an overarching paradigm within which the process of families dealing with their relatives who suffer from mental illness can be understood. A primary difference is the idea of perpetual motion in my model. Coming to terms with mental illness finds the family member unable to release his or her relative because of the chronic nature of the disease. There is no ultimate freedom or release for the family member.

The possibility for usefulness outside of the context of families with relatives who are suffering from mental illness may exist in my model. Individuals who are experiencing other life crises such as trauma, chronic grief, terminal illness, threatening events, or even divorce may progress through similar stages. A

variety of stage models exist that attempt to explain people's [emotional] reaction to life crises (Kessler, Price, & Workman, 1985). Although no agreement has been reached among theorists as to the validity of such models, and there is no support for their postulations, "there is a pervasive belief among caregivers and helping professionals that such stages exist" (p. 537). This study reinforces that conviction.

<div align="center">*Practice*</div>

The study highlights the need for mental health providers to be sensitive to the family's lived experience as they relate to the family member with mental illness. The individuals in this study recounted the demoralizing and often demeaning impact of not receiving the expected collaborative and cooperative involvement from the professionals in the field because their role as part of the treatment team was disregarded.

In Helen's narrative, she cited the importance of the intervention by the university psychiatrist on

behalf of her son as one of the most significant events in her experience. This experience also included a conversation with and initiated by the doctor, who established the importance of her role and participation in her son's treatment from the beginning: "Come up and get a motel room and take him there." This study emphasizes the need for mental health professionals to be aware of the significant part family members can play in their relative's healing and rehabilitation. It also calls for clinicians treating individuals with mental illness to pay particular attention to the familial contexts in which those with mental illness live and/or interact, so that treatment can be individualized and tailored to the specific needs of the individual and family.

Application of my model of meaning and its six identified stages can also inform and influence practice. My model of meaning can provide an important framework for mental health professionals in working with families much like the model of grief formulated by Kübler-Ross. The application of my model serves

people in being able to accept their own process and

to have more awareness; to know that they are not the

only ones; that other family members go through a

similar process. Treatment embedded within my model

can normalize an otherwise confusing and indefinable

event and transform the outcome. It is very important

for mental health practitioners to be aware of the

unique journey experienced by these families and

respond with a therapeutic container for the

inevitable consequences of dealing with mental

illness. Utilizing my model to inform treatment would

provide a structure for families seeking closure—if

this is ever possible—or at least resolution. This

would act as an extension of family therapy, for as

the individual finds his or her way a vicarious impact

may occur within the system.

Psychosocial implications for successful

treatment may expand to include a greater recognition

of the importance of family relationships and

connections. The maintenance of a functional family

system is vital in the treatment of mental illness.

Because families play the most significant long-term role in the lives of their relatives who are suffering from a mental illness it is necessary for this environment to be supported and cared for.

Research

The study of the search for meaning in family members who experience a life crisis similar to the chronicity of mental illness is an increasingly important area of exploration in health psychology, sociology, and medicine. Application of the findings of this study to other crises, traumatic and threatening life events, particularly those of a persistent nature is appropriate and certainly indicated.

This study suggests additional important opportunities for research into the experience of the family in crisis. In particular, the question of whether families are able to successfully reach resolution in the presence of other lasting events by utilizing the stages of meaning-making identified in this study is of importance. It would be useful, for

instance, to conduct studies examining whether or not family members dealing with chronic illness or disability employ similar stages of meaning-making.

Experience of the Researcher

Using self-disclosure as a means of allowing participants to understand a shared frame of reference between participants and Researcher was utilized with caution. I shared with a limited number of participants the existence of mental illness in my family and only as a vehicle for providing a feeling of *sameness* and reduce the stigmatizing effects.

As a licensed therapist, I anticipated that during the interview process I might experience the desire to provide therapeutic intervention to my participants. In fact, on more than one occasion I was so profoundly moved by what I was hearing that I wanted to provide relief for the obvious pain and distress that was being expressed by the interviewee. I also felt the desire to correct misconceptions, labels, and facts about mental illness, the act of

which would have certainly been disrespectful and interfered with the flow of the narrative.

The experience of being with 8 men and women in the interview setting, where and when each one was sharing information with potential for reactive emotional fallout, was slightly intimidating because of the vulnerability they entrusted with me. But I felt that my participants had accorded me a great honor in sharing their stories and given me a gift in the sometimes difficult content of their narratives. I found that some of the immediate effects for me were the re-stimulation of thoughts and feelings related to mental illness in my own family. I was able to process this in my own therapy as well as informally in generic conversations with other colleagues and friends. I don't believe my response to the narratives of my participants created an obstacle to retaining my objectivity and impartiality in the analysis and subsequent findings of my study. Rather, the experience served to enhance my scholarship and

support my empathy for families and their relatives with mental illness.

Limitations of the Study

While the narratives of the men and women in my study reveal much about the lived experience of 8 individuals with the common experience of a family member with mental illness living in the environs of a small American city, it is important to remember that qualitative research does not attempt to form generalizations. Instead, qualitative research pursues discovery and the emergence of theory in its outcome (results). The findings of this study may have relevance to similar populations but there are some aspects that could be viewed as limitations in the study protocol.

Study participants were required to have a functional reading level sufficient to complete a demographic questionnaire (determined by administration of the WRAT-IV-READ) and psychiatric stability (determined by administration of the BDI-II). An 8th grade reading level was considered

functional, which all participants exceeded, and
psychiatric stability fell in the *non-depressed* range
of the BDI-II for the general population with an
average participant score of 15. These educational and
psychiatric limitations would naturally eliminate
individuals with scores outside these ranges.

The age range of participants in this study was
between 33 and 75 years of age. The mean age of the
study participants was 59.5 years of age. Therefore,
one limitation of the study is that it did not include
more participants younger than those in this age
range. For this study, the Researcher recruited 8
family members (parents, siblings, children, and
extended family members who had raised a niece/nephew
or grandchild with mental illness) having a relative
in the immediate or extended family with a
schizophrenia spectrum disorder, bipolar disorder,
mood disorder, or anxiety disorder (as defined by DSM-
IV-TR criteria) who were 18 years of age or older.

Participants in this study were solidly middle
class, educated, white-collar professionals, and

resided in a geographic area that could be described as somewhat privileged. The participants were also almost completely racially homogenous. Another limitation of this study then was that it did not include individuals from other geographical environments (rural and semi-rural areas, larger cities and suburbs, etc), individuals who were representative of other SES as well as educational and vocational, and a more racially diverse sample of the population.

Conclusion

Eight men and women living with a family member suffering from mental illness provided narratives of their lived experiences with a serious mental illness. Results of the study indicated that family members come to terms with or are in the course of finding meaning in the midst of familial mental illness through a process that incorporates the succinct concepts of emotion, resources, knowledge, strategies, process, and coming to terms in an evolving phase sequence. The integration of these components into a

model of meaning for families who have members with mental illness lead these individuals to ways of being in the world that is characterized, in most cases, by active engagement in the search for meaning.

Serious mental illness is undeniably difficult and daunting to live with. Families confronted with such a challenge come face-to-face with the range of human emotion as they investigate explanations for their lived experience and look for a structure or container in which to place the tragedy they have encountered, or may continue to encounter. At times the intensity of their journey feels too overwhelming and there is a sense of desperation in the struggle. At other times they hold it together out of a sheer force of will or in the simplicity of the mundane. At either end of this spectrum, the families with relatives who are suffering from a mental illness are certainly more than conquerors and exhibit an almost indefinable grace and capacity to confront and live through sadness, worry, pain, and frustration while still managing to find meaning.

To live without Hope is to Cease to live.

Fyodor Dostoevsky

Their Voices—The Families Speak

Just shape up!

Life is what you do with what you've been given.

Because you can't change it,

take responsibility for it,

be actively involved.

It is so disruptive,

it's hard coping with it.

People don't know how to cope.

I thought I could have more influence,

it's just that you cannot control another person.

Oh my God!

Didn't I just have this conversation with myself?

I felt like someone had just banged a gong in my head.

I would not talk about it for a long time;

it was sort of a shame.

It scared the hell out of me!

He/she has a mental illness.

What do we do now?

We tried to figure out what to do,

not take it so personally.

We tried to maintain.

We just went on.

Charlotte, Chris, Debra, Dennis,
Helen, Jennifer, Marie, & Tom
2008

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APPENDIX A

CONSENT FORM

Project Title: **To explore the effects of mental illness on family members.**

Project Investigator: **Katherine Burrelsman, M.A.**

Dissertation Chair: **Cheryll Smith, Ph.D**.

About this consent form

Please read this form carefully. It tells you important information about a research study. The project investigator will also talk to you about taking part in this research study. People who agree to take part in research studies are called "subjects". This term will be used throughout this consent form. If you have any questions about the research or about this form, please ask. If you decide to take part in this research study, you must sign this form to show that you want to take part. You will be given a copy of this form to keep.

Why is this research study being done?

The purpose of this research study is to explore the effects of mental illness on the family. We are asking you to take part because you as a family member have important and unique experiences to share. At the most 15 people will take part in this research study.

How long will I take part in this research study?

It is estimated that only 3 hours of your time will be required to complete this study.

What will happen in this research study?

- You will complete and return paperwork provided to you via U.S. mail.

- Project investigator will schedule appointment for the research interview if you meet participation criteria.
- You will complete a one-on-one interview with project investigator which will last approximately 90 minutes.
- If any follow-up interviews are necessary you will be contacted by project investigator.
- A final optional exit interview is available for those wishing the opportunity to debrief and will last no longer than 15 minutes. This interview, short of therapy, is a subject's opportunity to talk with project investigator about their thoughts, response to, and experience of participating in the research study.
- All interviews will be recorded **except** the final optional exit interview.
- Data collected will be kept and stored by project investigator in a secure location. <u>All</u> identifying information will be destroyed at the conclusion of the research study.

What are the risks and possible discomforts from being in this research study?

There are no foreseeable risks or discomforts that may result from study procedures.

What are the possible benefits from being in this research study?

You may <u>not</u> benefit from taking part in this research study. Possible benefits to you might include the opportunity to share your personal experience. Future benefits may include contributions to mental health treatment, future research, as well as to individuals with mental illness and their families.

If I have questions or concerns about this research study, whom can I call?

You can call us with your questions or concerns. Contact information is listed below. Ask questions as often as you want.

Cheryll Smith, Ph.D. (Dissertation Chair) is the person in charge of this research study. You can call her at 805-962-8179 ext.334 and leave a message at any time. You can also call Katherine Burrelsman, M.A. (Project Investigator) at 805-897-6808 and leave a voice mail or send an e-mail to kburr09@yahoo.com with questions about this research study.

If you have questions about the scheduling of appointments or study interviews, call Katherine Burrelsman at 805-897-6808.

If I take part in this research study, how will you protect my privacy/confidentiality?

Your data will be identified with a random number and all personal information (name, address, phone number) will be stored on a password protected computer file. Only project investigator and dissertation chair will have access. All personal identifying information will be destroyed at the conclusion of the research study.

Limits of confidentiality: California state law mandates the reporting of suspected incidence of child abuse (Article 2.5 Penal Code 11165 and 11166) as well as "dependent adult" and elder abuse by your project investigator to California authorities. (Welfare and Institution Code, Sec. 15630).

Your Privacy Rights

- You have the right to decline to answer any questions or refuse to provide any information on written forms.
- You have the right **not** to sign this form permitting us to use your information for research. If you do not sign this form, you can not take part in this research study. This is

because we need the information of everyone who takes part in this research study.

- You have the right to withdraw your permission for us to use your information for this research study. If you want to withdraw your permission you must notify the person in charge of this research study in writing.

  If you withdraw your permission, we will not be able to take back information that has already been used. This includes information used to carry out the research study or to be sure the research is of high quality.

  If you withdraw your permission, you cannot continue to take part in this research study.

Consent/Assent to take part in this research study, and authorization to use or share your information for research.

- I have read this consent form.
- I understand that this study is of a research nature. It may offer no direct benefit to me.
- Participation in this study is voluntary. I may refuse to enter it or may withdraw at any time without creating any harmful consequences to myself. I understand also that the investigator may drop me at any time from the study.
- The purpose of this study is: **to explore the effects of mental illness on family members.**

If you understand the information we have given you, and would like to take part in this research study and also agree to allow your information to be used as described above, then please sign below:

Signature of Subject:

_____   _____
Subject   Date/Time

APPENDIX B

FORM B

THIS FORM IS TO BE COMPLETED BEFORE RESEARCH BEGINS

Insuring Informed Consent of Participants in Research: Questions to be answered by AUSB Researchers

The following questions are included in the research proposal.

1. Are your proposed participants capable of giving informed consent? Are the persons in your research population in a free-choice situation? Or are they constrained by age or other factors that limit their capacity to choose? For example, are they adults, or students who might be beholden to the institution in which they are enrolled or prisoners, or children, or mentally or emotionally disabled? How will they be recruited? Does the inducement to participate significantly reduce their ability to choose freely or not to participate?

   Yes, the participants in my study will be capable of giving informed consent. They will be 18 years of age or older, mentally and emotionally stable, and as volunteers, may choose to remove themselves from the study at any time. They will be recruited via letters and flyers sent to local mental health agencies and organizations.

2. How are your participants to be involved in the study?

   They will take part in 1:1 interviews with student researcher. Participants will also be required to complete, or have administered to them, a BDI-II, a WRAT-IV-READ, a Consent Form, and a Demographic Questionnaire.

3. What are the potential risks—physical, psychological, social, legal, or other? If you feel your participants will experience "no known risks" of any kind indicate why you believe this to be so. If your methods do create potential risks, say why other methods you have considered were rejected in favor of the method chosen.

   I do not believe that the participants in this study will experience any known risks. Participants will be interviewed about life experiences related to a family member with mental illness, which at most may be emotionally re-stimulating. An optional debriefing interview has been incorporated into this study to address any residual effects experienced by participants. As well, referrals will be provided to participants who feel a need for further consultation with a licensed mental health professional.

4. What procedures, including procedures to safeguard confidentiality, are you using to protect against or minimize potential risks, and how will you assess the effectiveness of those procedures?

   Participants' names will not be used in this study; rather they will each be given an identifying number which will be acquired from a random number website. During the course of research all study materials will be kept in a locked file to which only student researcher and dissertation chair have access. Any data stored on computer files will be password protected. At the end of the study all papers/data including participant's identifying information (names, addresses) will be destroyed.

5. Have you obtained (or will you obtain) consent from your participants in writing? (Attach a copy of the form.)

Yes. See Consent Form attached.

6. What are the benefits to society, and to your participants that will accrue from your investigation?

   The benefits of this study include contributions to the field of psychology, to research about mental illness, providing a chance for participants to be heard as well as possibly learning about heretofore unknown resources.

7. Do you judge that the benefits justify the risks in your proposed research? Indicate why.

   Yes. As I have already indicated, there are no known risks attached to study and therefore the benefits (contributions to the field of psychology, to research about mental illness, providing a chance for participants to be heard as well as possibly learning about heretofore unknown resources) are justified.

   Both the student and his/her Dissertation Chair must sign this form and submit it before any research begins. Signatures indicate that, after considering the questions above, both student and faculty person believe that the conditions necessary for informed consent have been satisfied.

Date:_____ Signed:_____
                               Katherine Burrelsman,M.A.
                               Student

Date:_____ Signed:_____
                               Cheryll Smith, Ph.D.
                               Chair

APPENDIX C

DEMOGRAPHIC QUESTIONNAIRE

Please indicate your response to the following
questions by selecting/completing the appropriate
answer that describes you.

What is your age: _____

What is your gender: ☐ Male   ☐ Female

What is your race: ☐ African/African-American
                        ☐ Asian/Asian-American
                        ☐ Caucasian/European-American
                        ☐ Hispanic/Hispanic-American
                        ☐ Native American
                        ☐ Other

Educational Level: ☐ High School Graduate
                        ☐ Some College
                        ☐ College Graduate
                        ☐ Professional Degree
                        ☐ Other

Household Income: ☐ Under $24,999
                        ☐ $25K-44,999
                        ☐ $45K-64,999
                        ☐ $65K-84,999
                        ☐ $85K-104,999
                        ☐ Over $105K

Marital Status: ☐ Single
                        ☐ Married/Remarried
                        ☐ Separated/Divorced

Employment Status: ☐ Employed FT
                        ☐ Employed PT
                        ☐ Retired
                        ☐ Unemployed
                        ☐ Student

Demographic Questionnaire-continued

Job Type:　　　　　　　　☐ Clerical/Office Worker
　　　　　　　　　　　　☐ Engineer/Architect
　　　　　　　　　　　　☐ Healthcare/Mental Health
　　　　　　　　　　　　☐ Manager/Executive/Business
　　　　　　　　　　　　☐ Sales/Marketing
　　　　　　　　　　　　☐ Small Business Owner
　　　　　　　　　　　　☐ Teacher/Professor
　　　　　　　　　　　　☐ Laborer/Construction
　　　　　　　　　　　　☐ Other _____

Do you have children? _____

If so, what gender(s)? _____
What age(s)? _____

What relationship is your relative with mental
illness?_____

When did you notice something was wrong? _____
　　　　　　　　　　　　　　　　　　　　Date
How old were they: _____
　　　　　　　　　　　　Age

How old were you: _____
　　　　　　　　　　　　Age

What was it that you noticed? _____
_____
_____
_____

When was your first professional contact? _____
　　　　　　　　　　　　　　　　　　　　　Date

Diagnosis(es)? _____
　　　　　　　　　　　　　　　　　　　Date

How would you improve this research?

For the following questions, please use the scale below to rate your responses:

```
  0    1    2    3    4    5    6    7    8    9    10
Minimal                                          Very
                                                Severe
```

(For example: If you feel you are presently coping very well, but you "sometimes get the blues", that would <u>probably</u> be a 4 or a 5.)

On a scale of 0 to 10, how would you rate the severity of your relative's symptoms at their worst?
0 = minimal to 10 = very severe _____

On a scale of 0 to 10, how would you rate the severity of your relative's symptoms at this time?
0 = minimal to 10 = very severe _____

On a scale 0 to 10, how would you describe your response to your relative's diagnosis at the time?
0 = minimal to 10 = very severe _____

On a scale of 0 to 10, how would you rate your own personal sense of well-being (emotional, mental, physical) at this time?
0 = minimal to 10 = very severe _____

APPENDIX D

1:1 Research Interview

1)   Overall, what has been your experience with
      having a relative who has a mental illness?

2)   What was important about your experience or any
      turning points that occurred?

3)   Can you tell me about your life now? How is it
      different from before?

4)   What were you doing when you first learned your
      relative was suffering from mental illness and
      how did you react?

5)   What happened after you discovered that your
      [relative] was suffering from mental illness?

6)   How did you cope with this experience? Could you
      take me through this process? I am interested in
      a typical day.

7)   What have you learned from this experience? How
      have you changed and did any good come out of
      this experience for you?

8)   Is there any advice you could give to someone
      else in the same situation that you believe would
      be helpful for them?

9)   Are there any suggestions to society-at-large
      that would be helpful? What could society learn
      from you and your experience?

10)   Is there anything that you would like to offer to
      this study that I have not asked you?

Throughout questioning, utilize probes (completion, clarification
and elaboration) and follow-up questions on new ideas, missing
information, and stories that seem relevant to research.

APPENDIX E

RECRUITMENT LETTER

Dear Potential Study Participant:

 I am a doctoral student in clinical psychology at Antioch University, Santa Barbara and have previously worked in the mental health field serving individuals with mental illness. As part of my Psy.D. requirements, I am conducting a dissertation study on what it means for family members to live with a relative who has a serious mental illness. My research is supervised by my Dissertation Chairperson listed below.

 I am seeking individuals over the age of 18 who are related by blood or adoption to a family member who has a serious mental illness (schizophrenia spectrum disorders, bipolar disorder, OCD, or major depression). Participation in this study will involve completion of certain required forms and tests as well as in-person interviews with me. There will be one required interview lasting approximately 90 minutes and two optional interviews lasting approximately 15-30 minutes each.

 Two interviews may be pre- and post-study assessments, and in the third interview I will ask you what it is and has been like to live with a family member who has a serious mental illness. Your name and any other identifying information will be kept strictly confidential. The total time involved in participation will be no more than approximately 3 hours.

 If you would like to be considered for participation in this study, please contact me via voice mail pager at (805)897-6808 or by e-mail at kburr09@yahoo.com. If you respond, I will contact you by telephone to discuss the details of my research

study further and answer any initial questions that
you might have.

  Thank you for considering this request.

Very truly yours,

Katherine Burrelsman, M.A.

Researcher: Dissertation Chairperson:
Katherine Burrelsman, M.A. Cheryll Smith, Ph.D.
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APPENDIX F

FAMILIES OF INDIVIDUALS WITH MENTAL ILLNESS

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‡ Take part in research ‡

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Doctoral student seeking immediate family members (parents, children, siblings) to participate in dissertation study exploring the impact of mental illness on the family

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See attached recruitment letter for contact information and specific criteria for participation

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