Metaphorical Language and the Nature of Hope among Mothers of Children who deal with Mental Illness

by

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ABSTRACT

A qualitative study of mothers' experiences raising a child who dealt with mental illness is presented. Twelve (n=12) mothers participated in this grounded theory study. Metaphorical analysis was used to understand how mothers conceptualized mental illness and hope. Mothers described mental illness in both static and dynamic terms, meaning that for some mental illness was primarily a fixed entity, or a "fact of life," whereas for others, mental illness was an active entity that maneuvered to change their children's and their own lives. Mothers described hope in terms of striving for presence, "normality" and productivity. Emotional experiences of mental illness, grief and loss, and stigma were also discussed. Recommendations for further research are made.

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Chapter 1: Introduction

"The preoccupation with categorizing and diagnosing mental illness has led to an emphasis on the tangible and objective, and a corresponding de-emphasis of the subjective, emotional, spiritual and symbolic" (Young, Bailey & Rycroft, 2004, p. 191).

Current conceptualizations of mental health and illness focus on the diagnosable individual. However, individuals who deal with mental illness also have families, friends, partners and other loved ones who are affected by their experience of the mental illness. Minimal research exists on loved ones' experiences of mental illness. This is problematic because as Cowling, Edan, Cuff, Armitage and Herszberg, (2006) state: "the unwell person is enmeshed in a family context. The distress of the unwell person is also the distress of the family. Clinicians should be acutely interested in the family context" (p. 416).

Research on the importance of family involvement in mental health treatment is in its infancy (Finke, 2004; Furman & Shukraft, 2007). While various studies have been done on the effectiveness of different psychoeducational interventions for families and families' satisfaction with various elements of the social service system (Dixon et. al., 2004; Gerson et.al., 2009; Hoadgwood, 2005; Kessler & Ackerson, 2004; Wahl, 1995; Yamashita, 1998; Wong, et.al., 2009), little research has been done on the lived experiences of family members of individuals who deal with mental illness.

In addition to the immediate context of the personal and relational stress involved with a current episode of mental illness, genetic research suggests that families may be experiencing that stress within the context of generational stigma; if a family member of this generation is dealing with a mental illness, chances are, one of their ancestors did as well (Boursnell, 2007).

Finally, given that mental illness has been and continues to be stigmatized in a number of cultures and settings (Chang & Horrocks, 2006; Corrigan, Miller & Watson, 2006; Feldman & Crandall, 2007; Gibson, Abel, White & Hickling, 2008; Hinshaw, 2005), understanding how stigma relates to the day-to-day coping of individuals and family members would seem to be paramount to providing quality treatment.

This research paper explores the day-to-day experience and coping of family members of those who deal with mental illness. Initially, recruitment for this study was focused on parental-couple dyads, with the intent of examining how individual, parental and couple experiences change after children are diagnosed with mental illness. However, fathers could not be recruited to participate and the focus changed to mothers' experiences This will be discussed in more detail under the "Procedures" section of this study. Qualitative interviews were completed with twelve mothers of children who deal with mental illness. As a grounded theory study that used the constant comparative method, findings were continuously compared with previous interviews (Holliday, 2002). Open coding was used to identify general themes in the interview transcripts. Metaphorical analysis was used to understand conceptualizations of mental illness and hope. This study is a response to the need to improve understanding of how mothers of children who deal with mental health issues conceptualize and experience mental illness, stigma and hope.

Researcher's role

The importance of the person of the researcher as the primary tool in qualitative research calls for an explanation of the experiences and assumptions the researcher brings to the subject studied (Holliday, 2002). Firstly and importantly, I am a child of someone who deals with a mental illness. Growing up with a loving parent who dealt with a mental illness affected me. My interest in this project grew out of knowing that my family and I have all been affected by mental illness. In spite of the assumptions and conclusions demonstrated by most psychological research, mental illness is not necessarily individualistic in its effects. The systemic story of mental illness is currently absent from the literature. Additionally, as a young therapist and a family member of someone who deals with mental illness, I know that the way I think about mental illness has been different than some of my peers and colleagues. I have personal awareness of the roles that stigma and hope play in the lives of such families.

In addition to my personal experience with my family and mental illness, I have spent the last four years working in residential treatment facilities conducting inpatient milieu treatment with adolescents who deal with severe and persistent mental illness. While in that role, I have engaged with parents to build alliances between the treatment facility and the family, and ultimately both lower the likelihood of relapse and prepare families for how to deal with relapse when/if it occurred post-discharge.

In my professional interactions with adolescents who deal with severe mental illness and their families, I have found that families generally love their children and want the best for them. At the same time, they often feel resentful, ashamed and angry about the effect their child's behavior has on them and their families and communities. My interpretations of the families I have worked with are undoubtedly flavored by my own experience interacting with others who deal with untreated mental illness.

While I have worked with individuals and families in mental health crises, I also have friends and family with well-managed mental illnesses. My interactions with them are not dissimilar to my interactions with friends who do not carry a diagnosis. In my experience, effective treatment and management of mental health symptoms makes a positive difference in systemic interactions.

These experiences and assumptions were constantly named throughout the research process and acknowledged while conducting ongoing data analysis. To temper the power of these assumptions, a number of external auditors and peer debriefers were used.

Chapter II: Literature Review

When conducing grounded theory research, it is important to minimize the influence prior knowledge has on interpretations of primary data, such as interviews (Creswell, 2009). Due to this, the literature review began after most interviews were complete and was developed to reflect topics that arose during the interviews. Electronic searches were performed using the databases EbscoHost and Google Scholar from November 2010 to January 2011. Search terms included “family mental illness”, “families mental illness”, “family mental health”, and “families mental health.” Forty-four full-text, scholarly and peer-reviewed articles were found and reviewed for this study. Additionally, colleagues and research participants recommended a number of books. These books were obtained and read. Topical categories for the acquired research included: qualitative research techniques, evaluations of family treatment programs, systemic recommendations for mental health providers, mental health provider beliefs about mental illness, cultural considerations, human development, expressed emotion, stigma, grief and loss, experiences of mental illness and hope. The interviews conducted for the present study connect to this research by adding voice to many of the concepts discussed and adding to the body of literature on hope. This study will discuss the categories most related to mothers’ conceptualizations of mental illness as identified in the existing literature: experiences of mental illness, stigma, grief and loss, and hope. Mental illness and associated stigma is experienced at personal, microsystemic and macrosystemic levels. All levels will be discussed.

Personal Experiences of Mental Illness

> So why would I want anything to do with this illness? Because I honestly believe that as a result of it I have felt more things, more deeply… But normal or manic, I have run faster, thought faster, and loved faster than most I know.
>
> Kay Redfield Jamison*, An Unquiet Mind: A Memoir of Moods and Madness, 1995, p. 218*

Whenever a discussion of mental illness occurs, it is important to remember that mental illness is often episodic in nature and typically varies in intensity (Hinshaw, 2005). Unfortunately, much of the research on mental illness ignores this reality and instead, treats diagnoses as constants in clients' lives. Unsurprisingly then, given the research climate, personal experiences of mental illness are colored by the disparity between the images projected by both wider culture and reductionist paradigms and the day-to-day realities of individuals' lives. Because of the pervasiveness of stereotypes of mental illness, a discussion on personal experiences of it also cannot be separated from the related discussion on stigma.

Research that focuses on the experiential element of mental illness is limited. Wisdom, Bruce, Saedi, Weis and Green (2008) reported that for individuals who deal with mental illness "the disregulation between the private self and public self… creates a great sense of crisis" (p. 490). For some individuals, there is a sense of loss and making the illness a part of their identity may be part of the grief process. "Normalcy" is seen as the goal; in short, individuals work to "pass" as "normal" (Wisdom, Bruce, Saedi, Weis & Green, 2008, p. 492). The symptoms associated with the mental illness can be extremely disruptive, not only to daily activities or function, but to sense of self. One participant in Wisdom, Bruce, Saedi, Weis and Green's (2008) study stated that the disorder they deal with "literally steals me from myself. [It] executes me and then forces me to look down at my corpse…" (p. 491). Other quotations offered in that study reflected a similar level of intensity. The mundane elements of dealing with a mental illness, such as maintaining a medication regimen or periods of time between episodes of mania or depression, were not discussed. A holistic picture of the lives of individuals who deal with mental illness appears to be absent from current research.

Other research on personal experiences of mental illness focused on recommendations for healthcare providers and social service agencies. Clarke, Dusome and Hughes (2007) described the often chaotic and stigmatizing experience individuals who deal with mental illness have in hospital emergency rooms. Patients who report to emergency rooms with mental health concerns often take a longer time to assess than patients with physical concerns. Clients who have utilized the emergency room services report a belief that mental health needs are triaged at the bottom of the list. This is corroborated with average wait times for mental health patients; it is not unusual for individuals to wait for 8-10 hours. Patients who dealt with a diagnosed mental illness reported that even if they were reporting with a physical concern, they were considered psychiatric patients. Boursnell (2007) confirms this, reporting that a parent who deals with pre-existing depression may struggle to get treatment for post-partum depression (2007). The negative experiences patients have in hospital emergency rooms are important for social service providers to consider and change because how clients are treated in the emergency room affects their views of the whole mental health delivery system. For many individuals and families who deal with mental health issues, the emergency department is their introduction to the entire system (Clarke, Dusome & Hughes, 2007).

After their introduction to the mental health delivery system and diagnosis, individuals work to maintain quality of life. Quality of life predictive factors identified by individuals who deal with mental illness include: purposeful work, connectedness, financial security and advocacy (Corring, 2002). Consumer advocacy groups, such as the National Alliance on Mental Illness, or NAMI, have been invaluable, not only in building connectedness among individuals and families who deal with mental illness, but also working to change institutional and cultural biases against those individuals and families (Bowland, Hensely, Johnson & Fleming, 2010; Drapalski, Leith & Dixon, 2009).

Microsystemic Experiences of Mental Illness

Mental illness affects not only the individual who personally deals with it, but that individual's family and friends. Research on microsystemic experiences of mental illness has generally focused on recommendations for social service providers and caregiver burden. Little research has been completed on the wider lived experience of family members and loved ones who may or may not be primary caregivers for individuals who deal with mental illness.

Familial caregivers of those who deal with mental illness report a variety of experiences and outcomes. The care giving experience, as perceived by caregivers, is at once described as stressful, unsatisfying and upsetting, and at the same time critical and therapeutic (Chang & Horrocks, 2006). When an individual presents with mental health concerns, it is not typical for family supports to be immediately offered. Additionally, it is rare for family members to report their own needs (Heru, 2000). Parents and families of those who deal with mental illness may be reluctant to seek psychotherapy for themselves, possibly because of a denial of their own trauma or the belief that their loss is not worth mourning (Burkhalter, 2010). A psychotherapist who wrote of that loss described his own experience parenting a special needs child as trauma: "There is the initial trauma, which for us was the realization that those silent ten fingers/ten toes prayers had gone unanswered…" (Burklalter, 2010, p. 23).

Siblings and others who are not direct caregivers also report loss, and like caregivers, their loss often goes unnamed (Abrams, 2009). Siblings may experience ambiguous loss, or grief without end, because the pain and denial attached to the disorder makes its effects unspeakable. Survivor guilt is common for siblings (Abrams, 2009). Jeanne Safer was quoted in Abrams (2009):

> Having a damaged sibling marks you. No matter what you achieve, where you go, or who you love, that other's life remains your secret alternative template, the chasm into which you could plunge if you misstep… (p. 307).

Macrosystemic Experiences of Mental Illness

In general, individuals and families of those who deal with mental illness in individualistic cultures describe their experiences as "lonely" (Abrams, 2009; Yamashita, 1998). When their loved one receives a diagnosis, it may be a family secret and coping with it remains covert (Abrams, 2009). In contrast, for Japanese people, informal supports strengthened the relational bond following diagnosis. When changes occurred, they occurred on a social level (Yamshita, 1998). Immigrants may have particular struggles dealing with family members' mental illness due to the dual stressors of caring for someone with mental illness and learning to live in a new country (Endrawes, O'Brien & Wilkes, 2007). Dual stressors also affect the narratives of African-Americans (Ward, 2009). Research found that African Americans are at greater risk of dealing with mental illness because of negative sociopolitical experiences, such as low income and multiple role strain (Ward, 2009).

Building connectedness and social acceptance for those who deal with mental illness is an important goal because social support is so apparently vital to goals as diverse as caregiver sustainability and achieving mental health parity in health insurance (Feldman, 2006; Suresky, Zausziewski & Bekhet, 2008). In spite of the loneliness of the experience of dealing with mental illness in an individualistic culture, few families in the United States are untouched by it (Suresky, Zauszniewski & Bekhet, 2008).

Personal and Internalized Stigma

The stigma around mental illness may contribute to loneliness. Individuals who experience mental illness experience stigma in a number of ways. Stigma is defined as “an attribute which is deeply discrediting; the stigmatized person is the bearer of a ‘mark’ that defines him or her as deviant, flawed, limited, spoiled, or generally undesirable” (Feldman & Crandall, 2007, p. 138). Consequences of stigma include “aversion, depersonalization into stereotypes, condescension and prejudice” (Gibson, Abel, White & Hickling, 2008, p. 27). Individuals who experience stigma may also experience symptoms as varied as “family discord, job discrimination and social rejection” (Feldman & Crandall, 2007). Related to the effects of stigma, individuals who experience it may be reluctant to seek professional help, work to conceal their symptoms and eventually, agree with their devaluation by society (Gibson, Abel, White & Hickling, 2008).

Victims of stigma also are often considered to be morally derelict. However, in individualistic cultures, individuals who experience symptoms believed to be associated with a biological cause do not experience such intense stigma. (Feldman & Crandall, 2007; Hinshaw, 2005). An example of that would be the relatively minimal stigma that individuals who deal with

Alzheimer's Disease experience; because it is viewed as a disorder that is primarily biological in basis, individuals who deal with it are not thought of as being personally responsible for their behaviors. However, there is no evidence that conceptualizing mental illness as biological in origin is clearly correlated with humane or cruel treatment of individuals who experience it (Hinshaw, 2005).

Microsystemic Stigma

Family members and loved ones of those who experience mental illness also experience associative stigma, that is, stigma associated with knowing or being related to someone who experiences mental illness (Wong, et. al., 2009). Given the historical background on mental illness, namely "that for much of the 20th century, the predominant theoretical views in the mental health fields were that child mental disturbance was directly linked to faulty parenting" (Hinshaw, 2005, p. 715), it is unsurprising that family members would experience the described stigma. Although these theories have largely been disproven, family members continue to be blamed for mental illness in the system, both explicitly and implicitly (Finke, 2004; Marshall, Solomon, Steber & Mannion, 2003). Family members may attempt to hide their member who deals with mental illness. Additionally, the children of people who deal with mental illness may be viewed as tainted (Feldman, 2007).

Family blaming cannot be adequately discussed without considering the theory of Expressed Emotion, namely that relapses among psychiatric patients can be caused by specific familial behaviors (Hooley, 2004). Validity research on expressed emotion is mixed, with some research suggesting that high emotionality among family members contributes to relapse and others suggesting that the high degree of emotionality demonstrated by family members during relapse is an effect of the relapse, not the cause (Hooley, 2004; Kawanishi, 2005; Marshall, Solomon, Steber & Mannion, 2003). The diathesis stress model is often used to describe the etiology of mental illness. In that model, individuals are described as being born with a genetic range of likelihood for developing any sort of biological or neurological effect. For instance, an individual may be born with a genetic athletic range that would make them able to run at one mile per hour to seven miles per hour. Whether or not they run at the high end or low end of that diathesis, or range, is determined by environmental factors, including diet and exercise. In this example, while general diet and exercise factors play into their phenotype, there is no specific food that will absolutely increase their speed. In the same way, while general environmental factors, such as stress or relationship quality, may contribute to whether or not someone develops a mental illness dependent on the interaction between their environment and genotype, specific behaviors of specific people do not seem to "cause" mental illness. In short, while the diathesis stress model is commonly used to describe the etiology of mental illness, it is often misapplied to suggest that specific behaviors of family members are associated with its onset (Ferris & Marshall, 2003). While psychoeducational interventions have been shown to be helpful for families, the vernacular of "treating" them may contribute to the "outdated and nonproductive" practice of family blaming (Marshall, Solomon, Steber & Mannion, 2003). Ferris and Marshall (1987) put it aptly: "Families of schizophrenic patients do not need to be 'treated,' but rather educated" (p. 112).

Macrosystemic Stigma

The World Health Organization describes stigma as one of the remaining greatest obstacles to the treatment of mental illness (Wong, et. al., 2009). Consideration of macrosystemic stigma must include the role that both expert and inexpert representations play in promoting and maintaining stigma. Experts on mental illness, including therapists, educators and policy makers, have a responsibility to be informed about current conceptualizations of mental illness and symptomology and ascribe them judiciously (Furman, 2007).

> Although the claims of primary labeling theory - that labels essentially create disorders through the branding of deviance - are likely to be overstated, denigrating labels do set in motion a set of expectancies and self-fulfilling prophecies that considerably worsen the initial deviance" (Hinshaw, 2005, p. 715).

Descriptions of mental illness should be descriptive and research-based. Researchers should strive for diverse samples. Policy research should be connected with the voices of the vulnerable it is completed to protect (Furman, 2007).

Inexpert representations include those promoted by wider media. Typically, mass media misinforms the public by using the easiest or most sensational descriptions for mental illness; an example would be when schizophrenia becomes split personality disorder. People who deal with mental illness are not represented as a part of the normal fabric of society and 75% of those represented in the mass media have no family connections (Wahl, 1995). This is simply not the case (Change, 2006; Corring, 2002; Suresky, Zauszniewski & Bekhet 2008; Wynaden, 2007). According to the United States Surgeon General (1997), "few families are untouched by mental illness" (p. 45).

Grief and Loss

> The stigma of mental illness minimizes both acknowledgement of the losses, and the community supports typically provided to people affected by less stigmatized trauma…” (Young, Bailey & Rycroft, 2004, p. 188)

Grief is central to the experience of the mental illness, but it is not regularly discussed in research literature (Boss, 1999; Young, Bailey & Rycroft, 2004). For individuals and families who experience mental illness, “a common theme… is that of loss and grief: grief for the loss of the person as known and the loss of hopes, wishes and aspirations, grief for the disability caused by the illness and the disruption to family and relationships” (Godress, Ozgul, Owen & Foley-Evans, 2005, p. 88). Factors that complicate the grief experience associated with mental illness include the inconsistent presence or absence of symptoms, the lack of community-based acknowledgement that something has been lost and the lack of ritual or explanation for the loss (Boss, 1999; Young, Bailey & Rycroft, 2004). It is important to not pathologize individuals’ responses to this type of complicated grief. Instead, it is important to stress that it is the situation and not the family that is “sick” (Boss, 1999).

Hope

Research on the conceptualizations of hope for family members and individuals who deal with mental illness is rare. Bland and Darlington (2002) present one study on how family caregivers construct hope. Family caregivers described hope as grounded in achievable reality and the present. It is also the “thing that would make a shift to something better” possible (Bland and Darlington, 2002, p. 63). Religious beliefs, folklore and other stories about why unpleasant things happen in the world are an important aspect of creating and sustaining hope (Bland and

Darlington, 2002; Boss, 1999). Professionals have the capacity to support and sustain hope or to destroy it (Bland & Darlington, 2002).

> Although the pain and impairment related to mental disability are undoubted, it is also the case that the symptoms of many mental disorders wax and wane over time, that periods of relatively normal function are prevalent, and that many persons with severe mental disturbances can make unexpectedly good life adjustments" (Hinshaw, 2005, p. 726).

> Ambiguous loss does not have to devastate (Boss, 1999, p. 17).

Chapter III: Methodology

Completing qualitative research with families in oppressed groups can be difficult because of the difficulty in recruiting participants (Minkler, 2002). This proved true in the case of this study, where the intended focus changed from an interest in couples' experiences of raising children who deal with mental illness to a focus on mothers' experiences, due to difficulty recruiting fathers to participate. The methodology of this study changed both in terms of sample and methods while it was completed. Use of an evolving methodology is typical in qualitative research (Creswell, 2009). Changes are tracked below.

The Qualitative Research Paradigm

There are a number of questions that delineate qualitative research. These include: "Who is the subject?" "Who is the researcher?" and "How do people come to know?"

In qualitative research, the first question, "Who is the subject?" is generally answered with people (Holliday, 2002). Whereas quantitative research holds a primary interest in presenting data that can be generalized, and therefore seeks to eliminate as many confounding factors as possible, qualitative research's primary interest is in deeply exploring a generally narrow population and/or experience. The goal of qualitative research is not to find widely generalizable results, but instead to initially explore an un-researched topic, population or phenomenon (Creswell, 2009; Holliday, 2002).

The second question is "Who is the researcher?" Qualitative research begins with the assumption that individuals who conduct research bring to the table their own sets of beliefs, prior knowledge and worldviews. The role that this a priori knowledge plays in the specific research design depends largely on the decision the researcher makes about paradigm, but regardless, the researcher names their assumptions and owns the role that those assumptions may play in their research (Creswell, 2009; Holliday, 2002).

The third question is "How do people come to know?" Qualitative research would say that people come to know by observing and engaging in the world around them. The first part of that assumption is that the best way to find out about the inner and outer world of a research participant is to observe them in their natural setting. The hypothesis emerges from initial interactions with the data and the participants, and further explorations of data continue to inform the evolving hypothesis or theory (Creswell, 2009; Holliday, 2002).

The final product of a qualitative research design should leave the reader with more questions than answers. It exists at the intersection of a specific group of people, a specific researcher or researchers, and a number of questions. It is bound by space and time. Qualitative research acknowledges the bound nature of its product. Although the initial interpretation of the data is conducted and presented by the researcher, further interpretations are expected and welcomed by lay readers and other researchers. Finally, as opposed to being reductionist in nature, qualitative research attempts to portray the holistic experience of a given population or phenomena. Just as qualitative research exists in context, the participants of said research are bound within the same context (Creswell, 2009; Holliday, 2002).

Grounded Theory Research

Grounded theory research is designed to develop an abstract theory of a process, interaction or action that is grounded in the experience of participants (Creswell, 2009). Multiple sources of data are utilized to gain a cohesive cross-section of the subject matter. The research process is characterized by continuous data analysis that allows emergent themes to inform future data. This data analysis can be within the data set or comparing the data to existing research on similar topics. The methodology evolves systemically as the research continues (Creswell, 2009).

Methods Specific to This Study

Participant Selection and Description

Before recruiting participants, all methods for recruitment and treatment of participants and confidentiality of research data was approved by the University of Wisconsin-Stout's Institutional Review Board (IRB). Participants were recruited using a variety of techniques including posting fliers at grocery stores, cafes and restaurants, and contacting local support group leaders for individuals and families that deal with mental illness. Research participants were also collected via my own social network, through Twitter, Facebook and email.

After participants found out about the study, they contacted me via email or telephone. They were contacted and screened to confirm that they had a child who dealt with a mental illness as defined by the American Psychiatric Association's Diagnostic and Statistical Manual-IV, text revision (2000), henceforth referred to as the DSM IV-TR. I chose to exclude physical disabilities or developmental disorders from this study due to validity concerns. No restrictions were placed on severity of the mental illness, age at onset or duration of the disorder. Fourteen (n=14) participants initially contacted researcher. One dropped out and one did not qualify.

The participants in this study consisted of twelve mothers of children who deal with mental illness (n=12). All participants were from the Midwest. One mother was adoptive and the rest were biological. The children's ages ranged from preschool to mid-adulthood. Five mothers were single, the remaining seven were coupled. From interview transcripts, it can be determined that mothers had dealt with mental illness for a range of less than one year to over thirty years.

Interview Question Development

The semi-structured interview consisted of five open-ended questions. The interview began with a grand tour question: "Please tell me what it has been like for you to have a child diagnosed with a mental illness." Use of a grand tour question is standard in grounded theory research (Holliday, 2002). Other questions were asked if they were not addressed in the first question and/or as follow-up questions. Interview questions included:

1) Please tell me what it has been like for you to have a child diagnosed with a mental illness
2) An example of a "personal philosophy" is "what doesn't kill you makes you stronger." What are some of the personal philosophies that have informed your

experience? How have your personal philosophies changed since your child was diagnosed?

3) What made your experience more difficult? What made it easier?
4) How did you help each other while you were going through this?
5) What advice would you give to parents who are going through the same thing you went through? About parenting? About being a member of a couple or maintaining yourself?

Mid-way through the data collection process, I realized that using the past tense during interviewing was inappropriate given the ongoing nature of parental experience. All questions were then phrased in the present continuous tense. Question format was kept flexible to allow me to follow the natural course of the conversation. Additionally, unscripted follow-up questions were permitted. Given the importance of privacy among individuals in this population, I decided to avoid collecting demographic data to further ensure participant confidentiality. Thus, data on participants' ages, racial or ethnic identities and income levels were not collected, nor was information about the range or kinds of MI diagnosed. All that is known is that the diagnosis fits within the DSM-IV TR.

All interviews were audio-recorded using a Flip Video Camera. No personally identifying visual footage of in-person interviews was collected. Telephone interviews were conducted using a cell phone. Transcripts were completed using Microsoft Word. Quicktime Player was used to play the audio-recorded interviews.

Procedures

Initially, only in-person interviews with couples were planned. Interviews would have included the same interview questions. After coding that round of interviews, I planned on returning to the couples to conduct a task activity that would have been observationally coded for couple characteristics.

However, many of the participants who initially contacted the researcher were single or divorced. Additionally, of those that were coupled, none of them were able to arrange an interview time that would occur with their partner. In light of this, the research was reconstructed to consider mother's experiences exclusively.

In-person or telephone interviews were arranged with participants at their preference and convenience. Originally, only in-person interviews with couples were planned. As most participants preferred telephone interviews, mid-way through the data collection process, telephone interviews were offered exclusively to maintain consistency in the process from that point forward. Of the twelve interviews conducted for this study, nine occurred over the phone (n=9) and three occurred in person (n=3).

During the interviews, participants were read the informed consent and signed paper copies during in-person interviews, or indicated verbal agreement during telephone interviews. Interviews lasted from thirty to ninety minutes, depending on length of time it took to get through the interview questions and ask follow up questions. Following the interview, all participants were offered the chance to add anything that was missed.

All interviews were transcribed by me within the week the interview took place. Selected transcripts were submitted to the research advisor for evaluation of language and adherence to confidentiality standards. All names and identifying information was bracketed in the transcripts, such as [NAME] or [LOCATION].

Reliability and Validity

Validity is concerned with the accuracy of the findings and a number of design choices were made to strengthen validity. It was enhanced by using peer debriefing to monitor the fit of findings with conclusions (Johnson, 1997). Peers were selected from my graduate class simply by asking who was interested in peer debriefing for this project and agreeing to work with the peers that were interested. Two peer debriefers were used throughout the process. This was done to temper my bias in interpretation. As qualitative research cannot be completed outside of a social environment, the section "The Researcher's Role" makes explicit the bias I brought to this research (Creswell, 2009), and research reflexivity was used to temper assumptions (Johnson, 1997). To ensure reliability, interview transcripts were checked for mistakes in two ways. All transcripts were read while listening to the recording and all transcripts were forwarded to participants for their review. Coding schemas were monitored consistently to be sure that any changes in coding were intentional.

Data Analysis

After each interview the researcher read the transcript for general themes to explore in future interviews. These themes were tracked in a personal journal that included both systematic and personal observations that occurred during the research.

Following all interviews, all transcripts were coded using an open coding process. Open coding is the process of reading data for thematic content. A goal of open coding is to build a theory from the ground up by beginning with themes that are close to participants' language and moving into theoretical formulations on the basis of those themes (Creswell, 2009). At the end of that coding process, 107 disparate codes were found which fell into six major categories: social services, help seeking, metaphor, roles and relationships, feelings, and meaning-making. Because all codes could not be adequately explored in one study, metaphorical analysis was used with codes that appeared to be directly related to conceptualizations of mental illness and hope. After the 107 different codes were identified in the first round of coding, I read all transcripts again for metaphorical language as it related to mental illness and hope. Metaphorical language was defined as concrete language used to describe an abstract entity. Metaphorical analysis explores the use of language as it relates to a given set of phenomenon. All metaphor both highlights and hides different elements of phenomenon (Lakoff, 1993). An example of this is the idiom "what doesn't kill you makes you stronger." That idiom highlights resiliency and hides negative repercussions of experiencing difficult circumstances. By using metaphorical analysis, researchers can gain insight into the constructions, values and meanings individuals attribute to abstract phenomenon.

Metaphorical analysis was chosen to analyze this study due to its strength in understanding conceptualizations of abstract phenomenon. "Mental illness," though at times concrete in its presentation, is an abstract phenomenon in that it presents very differently in different people, may be managed and experienced differently and is ascribed to a number of different etiologies across individuals and cultures. To understand how mothers make meaning of raising a child who deals with a mental illness, a good place to start is understanding how they talk about it, which points to the ways in which they think about it.

Chapter IV: Results

Mothers in this study described their experience as a mother of a child who dealt with a mental illness. Open coding was used to generate themes that categorize a variety of aspects of mothers' experiences. Six major categories emerged: social services, help seeking, metaphor, roles and relationships, feelings, and meaning-making. This chapter highlights two parts of that analysis: a broad understanding of how mothers' feel about their child's mental illness, and a metaphorical analysis of the ways women used to describe mental illness and hope. With any complex phenomenon people may use mixed metaphors to describe it (Lakoff, 1993). This proved true in this analysis as well. For the sake of brevity, I will use bold text to highlight the metaphors and themes that were most pertinent to this study.

Metaphor: Mental Illness as An Entity

Throughout all interviews, mothers used language that implied they conceptualize mental illness as an entity. An entity metaphor takes something abstract in nature, such as life, and characterizes it as something concrete, such as a journey. An entity metaphor highlights that something has concreteness, with boundaries, or a beginning and end, and may be experienced with the senses or intuitively. An entity may be fixed, such as a road, or it may be fluid, like a river (Lakoff, 1993). In the following sections, I'll be highlighting mothers' use of entity metaphors as they talked about their children's mental illness.

Fixed Entity Metaphors

Metaphors used to describe mental illness as a fixed entity highlight the idea that mental illness is consistent. They imply it is something that stays the same over time and isn't responsive to attempts to change it. For example, if someone was driving and they came across a boulder in a road, they would have to adapt to it. The rock would not change in any sudden or unpredictable ways. They could avoid the boulder by going around it, over it or taking a different road. Like this example, when mothers talked about mental illness as a fixed entity, they talked about adapting to it in predictable, learnable ways.

In the following example Kathleen[1] relates how she and her children have learned to adapt to and navigate around mental illness as a fixed entity.

> What my kids have found way more helpful is: "**I have different learning styles, I have learning differences, I have strengths and weaknesses, everybody's unique, me too**. These things are not necessarily handicaps, **there are ways to deal with them**. It may be harder for me to get through school in a traditional way. Maybe I'm a tactile learner, maybe I need multisensory stuff, maybe I need vision therapy to deal with dyslexia."

Fixed metaphors were also used for the labels used to describe mental illness. Labels are a different entity than the thing they describe. An example of a label would be a name tag; a name tag, though descriptive of the person wearing it, cannot be reasonably confused for the person. Two mothers, Kathleen and Alicia, described mental illness as a label. Kathleen spoke passionately about the importance of avoiding use of the words "mental illness:"

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[1] All names were changed from their original names and generated using The Random Name Generator, found at http://www.kleimo.com/random/name.cfm on March 18th, 2011.

> I think society at large has very…[2] negative… connotations associated with mental illness because of media, police activity. Um, we live in a neighborhood where we had a mentally ill neighbor who was schizophrenic and who precipitated a crisis and evacuation of neighborhood. It was very traumatic for everyone to see the SWAT teams set up next door and to have 50 canisters of tear gas pumped into our neighbor's house, and to think that everything we owned was going to disintegrate when he lit the torch and set the block on fire. So, when you go from that personal experience to movies of psychopaths and schizophrenics and grim murderers, I think that my kids tend to associate **the label mental illness**[3] with the most graphic, the most bizarre, the most serious kinds of illnesses… taking responsibility is a challenge and I think **the label mental illness** is scary, for anybody, parents and kids and neighbors and relatives, so **I just wouldn't use the term**.

Emma echoed Kathleen and suggested an alternative:

> I think with the whole thing with serious mental illness, and you know, I think a lot of people **prefer to use the word "brain disorder"** because they think it, it's less related to stigma and I'm kind of related to that side too.

In both of these examples, mothers appear to avoid using the label "mental illness" because of the stigma associated with its use. While labels cannot be confused for the entity they are meant to describe, connotation affects the experience of them. By utilizing different labels for symptoms associated with mental illnesses, mothers both avoid the

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[2] This quotation has been edited for readability.

[3] Bold font was added to denote text that highlights metaphorical use of language.

stigma associated with them and separate their children from the worst possible outcomes, of “grim murderers,” “psychopaths” and the like.

Alicia, spoke about labels as well, but spoke in terms of identifying and connecting symptoms with those labels:

> Being a trained therapist myself and knowing, just kind of knowing what’s normal and what’s not and maybe some other parents would overlook some things that **I’m more able to label**.

Fixed metaphors also imply that an entity exists in a consistent context, such as on a continuum. Alicia also spoke about what she had learned since her child had been diagnosed with a mental illness:

> Mental illness just sounds really serious and so, I guess I, when I would think of children with mental illness, before I was a parent, I guess I would think of kind of the extreme and the kids out there in the general public and you can just see them in the general public like oh there’s something not right about that kid. But there’s, **there’s this continuum**, very high functioning kids out there who have a little anxiety, a little depression

Interestingly, only three mothers exclusively used fixed metaphors. One used both fixed and fluid metaphors and the remaining eight used exclusively fluid metaphors to describe mental illness. Use of fixed metaphors over fluid metaphors may suggest more cognitive, as opposed to affective, processing. Fixed metaphors may be associated with dispassionate problem solving. Returning to the rock in the road metaphor used earlier, if a person is driving and finds a rock in the road, the solution is to somehow get around it. In the same way, if mental illness is placed in a consistent, predictable location, it too can be dealt with by problem solving.

Fluid Entity Metaphors

In contrast with fixed metaphors, fluid metaphors for mental illness emphasize a changeable and sometimes unpredictable course. A fluid entity can adapt or accommodate, or even take over its surroundings. Mothers who used fluid metaphors tended to describe mental illness in terms of how it behaved, could be outwitted or fought against. Unsurprisingly, given the changeable nature of mental illness in a fluid metaphor, mothers who used them often struggled with specific naming for the entity that was currently or had affected their child. In terms of specific metaphors, mental illness was described as a mask that could be put on or taken off, an eviction, an invasive species, an unstable element and an enemy. A number of mothers also spoke about the period when the mental illness was emergent, or something new.

The difficulty of noticing emergent mental health issues was noted by three mothers. These experiences point to the difficulty involved in recognizing that something is happening that is different from either their previous “normal child” or that child’s peers. Some spoke of mental illness as slowly emergent, like a season change. Just as the change from summer to fall can begin with rainstorms, cooler weather and different smells, mental illness can begin incrementally. Ada said:

> I guess, you know, **had I known** there was **something going on**, I probably would have been more aware, **something wasn't right**. Um, so yeah, it's kind of **hard to be aware of something that you aren't aware of** and don't know anything about.

Ivy spoke about raising her child from infancy and struggling to come to terms with the idea that her child "isn't normal:"

> When you are a parent with a child with a mental illness, you don't know what to do. Because it's so organic to the child. You raised this child from baby-ness. **You get used to the little quirks and you, I don't know, even come to treasure**. You know, as silly as this sounds, her rocking… she was so good and quiet when she rocked and it was a time out to me. And then when they reach the social world and they're compared to other children and other children have a say about them and you realize, **oh, maybe my child isn't normal and, and, you fight that.** You really **fight that**. And so, so it's **difficult to get your head above water long enough** to say, this person needs help. This is not normal.[4]

Rosemary grappled with the ambiguity of diagnosis, discussing the difficulty of determining the boundaries around the mental illness. She said:

> I want him to be able to get a job when he's 16, I want him to be able to get to his job. I want to say, I need a gallon of milk, why don't you run to the store and get a gallon of milk. **But then there's the part** where he's, well, you're not honest, you've been doing this, you've been doing that, but yet, it's also **part of growing up too**.

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[4] This is an example of a mixed metaphor.

In contrast to a slowly emergent mental illness, other mothers spoke of a clear realization that something was happening. This sudden awareness highlights the idea that mental illness as an entity can occur without warning. It also highlights the beginning of a mental illness as being time-bound, evident by use of singular determiners, such as "that" as opposed to "those." Interestingly, while Nancy described realizing that her daughter was dealing with an eating disorder, the onset appears to have occurred over the course of the year, but is still described as a single point in time:

> **That's** when the whole thing started. Sleeping all the time, um, and not eating at all. She'd keep journals and I'd go in her room and I'd look at them, because she never hid anything and I'd look at the journal and she had like, I can remember 500 calories one day. And **then as the year went on**, I can remember, she was down to 50 calories a day. And then she had just water, and then she didn't eat for two or three days. And **that's** when we were getting concerned and asking her questions and um, got her a shrink.

Emma spoke about her son's first psychotic episode.

> He kept himself very busy in terms of watching videos, having noise all the time, but um, **finally** he was moving his, he moved his bed into the living room because he thought that aliens were zapping his brain in the bedroom. And there was some kind of buzzing, and we looked and there was nothing.

Mental illness was described as being like a mask, or something that conceals an individual's real identity. As an entity, a mask is something that can be put on and taken off; while the look and feel of the particular mask may not change, its use does. This metaphor contrasts with the fixed "label" metaphor because while a label's purpose is to be descriptive, a mask's purpose is to obscure. Use of this metaphor highlights the idea that mental illness conceals a person's true identity and that it can be put on or taken off. Alison said, "I mean, um, he does things and says things that are hurtful… and **you don't know if he means them or if it's just because of the illness**. So that makes it very, very hard." Rosemary reflected on the same ambiguity: "[The counselor] says well **how much of that is just the teenager, how much is the, illness**." Brenda said succinctly: "I mean that's not who they are."

Related to the mask metaphor, mental illness was also described as an eviction from self, or something that separated an individual from him or her self without their consent, rather than simply masking who they are. This metaphor echoes the mask metaphor in that it highlights that mental illness can hide a person, but has more sinister undertones. Two mothers speak of mental illness separating their children from him or her self. Marilyn spoke of her desire that her son "**come back to himself**." In speaking about her daughter, Brenda echoed this idea: "It really took her almost a year **to get back to herself**." Eviction occurs without consent. In this metaphor, individuals are separated from themselves and have a self to return to, but that self is not simply concealed beneath a mask.

Mental illness was described as an invasive species. Invasive species are non-native plants or animals that have the capacity to upset a local ecosystem and deleterious consequences for that ecosystem. This metaphor highlights both the systemic impact of mental illness and the idea that it is not indigenous to the family. Ivy described how treating mental illness required treating the whole ecosystem:

> And the thing with the mental illness is that, is that **it is invasive**. **It invades all aspects of the family.** You have your "normal child," whose lives are being disrupted, who are not getting the attention they deserve because of this person, and yet you can't take your eye off the kid at all, so you can't give your other children any affection, the time any of the time, any of that. Um, so, it's, **it's not just an isolated thing** where you can get them help, they'll be fine.

Like an invasive species, mental illness was also described as something that may be present, but invisible and just as damaging. If something damaging is invisible, it requires constant vigilance. Marilyn spoke of mental illness as something possibly hidden, but still present and potentially a force to deal with:

> I'm not very good at analogies, but a long, long time ago I was in a car and the other driver hit the guard rail and I'm still to this day when other people are driving, I get afraid when they get real close to the edge. You know, I'm a little gun shy on it? And I guess in a way, I'm still a little gun shy. You know, I mean **time is on our side**, this is the longest period that he's done this well and he's, I mean everything is different. I'd say we have a new normal, but part of me has always been 'knock on wood.' So **I think it's kind of in my blood that I don't want to jinx it and I hope we don't have our head in the clouds**, **thinking that we're out of the woods**. I mean I told [our support group leader] the second time around that we had stopped going to NAMI meetings because I thought it was a one-time deal and we were done. She just gave me this little look and a little smile, and I knew she knew, because she's been living with this forever. But **mental illness is never done**, and it's just to what

> degree **is it showing its ugly head** … Like in my son's case they just weaned him to the point where they put him on lighter doses and then to a different med that was very light and now he's not on anything. And I think it's been six months, um, but I definitely keep all their phone numbers on hand.

A number of mothers used metaphors that spoke of mental illness as a volatile, unstable entity. Use of metaphors that describe mental illness as something that has to be "tip-toed around" suggest mental illness, the entity, can be scary, unpredictable and tempestuous. It is like a volatile chemical and can explode with the least obtrusive of environmental stimuli.

Alison and Nancy described walking softly.

> Everybody's been, **everyone's on edge**, because everyone's walking around, it's like everyone's **walking around on eggshells** because **you can set him off** at any time. (Alison)

> So it's always **kind of pussy-footing around… Everything we'd say, she'd blow up.** You couldn't talk about school. You couldn't talk about food. You couldn't talk about work because everything in her mind would revert back to food like we were trying to talk about food. So, we couldn't talk about anything. (Nancy)

Mental illness was also described as an enemy that required an active offensive to win against. This metaphor highlights the idea that mental illness can be beaten, not simply taken off or left behind. Ivy passionately described her response to her child's mental illness:

> You **have to stand up**. I would say anger got me through a lot of it. I was angry at this thing at different times, at different things **that got hold of my children**. And I guess if I had to put sort of a picture to it, I would say that **I was in a battle with this thing**, and by God, **I was not going to lose**. And you do lose. You do lose. This is an organic problem with your child, you don't have control over it. But you get up the next day, because you're **ready to do battle with it again.**

Discussing mental illness as a fluid entity emphasizes different qualities than discussing it as a fixed entity does. If an entity is fluid, it would require more flexibility and consciousnesses to cope with it. If an entity can learn or adapt, it may require strategy. Use of fluid metaphors for mental illness may be more common among mothers that see mental illness as anthropomorphized. When something has human qualities, it can be infuriating, charming and deceptive; in short, the experience of it includes affect.

Theme: Affective Experiences of Mental Illness

I have discussed the metaphorical analysis of mothers' conceptualizations of mental illness. Now, I will discuss mothers' feelings about their children's mental illnesses, which were determined through the process of open coding. After discussing affect, I will return to metaphorical analysis to discuss hope.

Devastation

All of the mothers discussed their feelings about their child's experience with mental illness. Emma discussed how the time leading up to diagnosis was difficult: "Well, as I said, my son has, has paranoid schizophrenia, a very classic case of it. But before the actual truly delusional thinking came out, things got very difficult." Glenda reported that when she found out that her daughter was dealing with a mental illness, it was "devastating."

> How it's devastating for me? Um, well I felt like I couldn't tell anyone, I don't want to say shame, but I know that there's a lot of stigma attached. **Devastating** because I didn't know how it would affect her life. **Devastating** in the fact that, there was nothing we could do to prevent it or to help it, just to get her support. Um, you know, we had to do research and um to find out what her future would be like. Um, it was **devastating** too because she has a dual diagnosis, and there's a lot of other problems associated with that. And then you wonder, what came first, the mental illness or the, or the other problems she's having.

Ivy's description of finding out about her daughter's reported suicidality echoed the devastation: "I remember when the teacher was telling us about this, I just, **I couldn't even hear her words** after she had talked about not wanting to live. You know, I just couldn't even, couldn't even hear that, whatever she said after that."

Living with mental illness was described as "hard" by two mothers. Rosemary described how "hard" it was to determine her son's specific diagnosis:

> I don't know if it's time to do more testing, so that part has been **really hard**. Just trying to find out what it is, and what we can do to try and help him. Um, so that I would say it's **hard**. Trying to figure out what can help him and not knowing.

One mother described dealing with crises precipitated by the mental illness as "hard." Brenda described mental health crises that occurred with two of her children:

> He came out of the Gulf War in bad condition and um, we, there were times when we couldn't live with him, he was very aggressive toward my husband, so we couldn't have him in the house and **that was hard**… Even though she was living with us, we couldn't get her the help that she needed. She didn't have any insurance, we had to start, we had to start real basic to get her what she needed. Actually, she was living here, went out on a walk, fell, and the police found her, brought her back to the house. She was almost comatose. Couldn't respond to him or me or anyone and he did end up taking her down to [the hospital] where she finally got the help that she needed. But, it had reached a point where she would just sit on the couch, you couldn't do anything with her, um, get her to um, go outside, or. She would get up and eat and that was about all that she would do. **So, it was really hard.**

Brenda added that reliving those crises was difficult, although both of them had long since passed. She said, "It's **hard**. Going back to talk about it. I think it in my head a lot, but it's hard to go back and relive it all again."

Confusion

Mothers discussed a desire to know what was going on with their children and the accompanying confusion. Brenda spoke eloquently about this dichotomy:

> So it's, they're very bizarre diseases because it's behavior that shows you what's going on. And it takes you some time to **figure out** the behavior when you don't

> have a history of it in your family; it's really **confusing** to people. Um, my husband kept saying, "if he'd only get a job, if he'd only go to work," but he actually wasn't capable of working because he couldn't concentrate enough. Even with medication, sometimes people can't do the things cognitively that they want to. And often if they've had many episodes, that has damaged the brain so that they're not able to get back some of the things that they were able to do. And yet, they look healthy. So it's, **it's really, it's confusing for people. It's hard to understand.** And other people, their peers, their brothers and sisters, they continue to do their thing. They go to college, they get married, they have children. And the others that are ill aren't able to do that, so it's real difficult. Hard to watch.

Marilyn echoed Brenda:

> Just, but its still, as much as I've studied about it and talked about it, I, it's still **confusing** to me, but it's still, he had these highs and lows in his moods and he didn't really seem to have a lot feelings and just, not at all like how he normally is. And so, that part of it was just so heartbreaking.

Cut-off

Mothers also spoke about feeling cut-off from their own feelings, a personal sense of efficacy, and other people. Alicia described feeling separated from her own emotions because of everything happening with her daughter:

> It's kinda, it's yucky, and it's really **isolating.** I think I mentioned it to her daycare provider, just mentioning, you know, she'll be out for a couple weeks in the spring.

> But you know, she doesn't know yet, so, you know, she just broke into tears when I told her… I tell her and then she starts crying and oh, I just feel so bad for her. **And here I am, her mother, and I haven't cried over it yet**, and I guess I probably haven't had time to.

Ivy described the cut-off from her own emotionality in mechanical terms: "And I just sort of **became this robot** that sort of just went through life, the rest of it, you know the rest of it was just, was just doing what I was told to do."

Four mothers discussed feeling powerless against the effects of the mental illness. Alison discussed how her son coming of age highlighted her feelings of powerlessness:

> It has been extremely, well before it was extremely stressful, because I felt like I had to be more engaged in him, but now that he's 18, I've had to step back because I'm no longer in charge of his medications or anything, which is **very hard**.

Nancy's words reflected Alison's feelings of powerlessness: "You worry about it every day and you wonder how she's doing and you see things that aren't healthy and **there's not a whole lot you can do about it**." Ada summed it up: "And so, there's a lot of frustrations with that, when you have a child that is ill and **there's really nothing you can do about it**." Marilyn spoke about realizing that she was powerless in terms of controlling her son's mental illness, and that needing to "let go" further was difficult:

> And not a day goes by that I don't think about or worry about it, but I know I can't control it, and I know he's, it's very important, he's 24 now. I know he's smart enough to know, what would happen if he chooses not to pay attention to what's

> going on in his head. But I guess as a parent, I can't do much more than just observe and bring things to his attention. I mean, I can't dwell on it. I do secretly sometimes, but I, I can't enable him. **You know I have to let go. That's the hard part.**

Mothers described a sense of cut-off from existing relationships and possibilities of other relationships. Alicia described feeling "**like an island**… in my own home and community." Rosemary described not connecting with a friend for support with her son's mental illness because of shame: "I could have that support from her, it's hard to admit it because **it makes me feel like a failure**. A lot of times. Because as a parent, you should be able to prevent that."

It is important to note that mothers also described exceptions to these negative emotional and relational consequences of dealing with mental illness. Those exceptions seemed to be associated with knowing more about the mental illness or anticipating diagnosis. Kathleen, an adoptive mother, described anticipating that her children would deal with mental health issues before they emerged.

> …**It's no surprise to me** that they have learning differences and that they have PTSD, ADD, which is really prevalent among adoptees anyway, or dyslexia or other things because of nutritional deficiencies and um, tremendous stress in infancy and toddlerhood. So, so **I'm not surprised**. **I anticipated** such diagnoses. **I participated** in the diagnoses. **I paid for** assessments that confirmed what I suspected and um, so I'm not surprised, **I am somewhat relieved** sometimes to have labels so that you can figure out what to do…

Although dealing with her children's diagnoses was an ongoing challenge, Kathleen described it as expected and a relief. In contrast with the ongoing nature of Kathleen's children's mental health issues, Ivy said that her daughter was her "hero," because she had "made it through this." This conceptualization points to metaphors other mothers used about hope, which will be discussed below.

Theme: Grief

Grief and loss were central to mothers' experience of their children's mental illness. More than half of the mothers spoke directly of the loss of dreams, opportunities and the child they had known. Ivy discussed reassessing her dreams for her child after diagnosis:

> Well, you know when you are given a baby and this is what I was talking about earlier, when you give birth or you adopt or whatever you're given this new little life, you have all these dreams about how it's going to be. And **when those dreams fall apart, you have to really reassess your definition of success.** And it can't be what other people, what you had, you know those dreams, they're exploded and that's really hard. And that's what I mean, when at six years old, you're thinking wow, that's not what I was thinking. Wow, that's a big dream, poof, my kid is not happy in a major way. And you know, a happy childhood has come to an end. You know, **I think I had to really reassess that.**

Brenda discussed the ongoing nature of the grief:

> I think **the grieving comes back and comes back**, you know? Um you see, maybe, a vacation, a birthday, I don't know, that you wish things were different or better.

Emma's description adds to Brenda's in discussing not only the ongoing nature of the grief, but also how mental illness has changed what it means for her to be an older adult:

> Some of my best friends to this day are other single moms from that class that [my son] was in from grade school and so with those parents and just with other peers, you know other people my age, the events in their family, the kids graduations and later on, weddings, ah, moving into really successful careers, um, ah, let's see, oh, now at this point having babies and maybe of my peers have the real joy of having grandchildren. It's like a little bit bittersweet. **I really consider it a spiritual practice for me to really feel joy and happiness for their success, and not focus too much on what's missing in my case and to really be honest about what's missing in myself.** My son has a horrible condition, a horrible disability. It's not his fault, it's not my fault and it means a very different lifetime for you know, ah, I mean, you know being somewhat financially dependent and then being dependent on me for rides and the other real thing is that I'm his only real friend, so he wants to just talk to me about whatever is in his head and if he does come over, like he walked over to my house before he came over yesterday, and he's just like blah blah blah blah, because he just wants to talk, he just wants to talk.

Nancy discussed how the ongoing nature of the illness means that her grief "never goes away." Emma described the contrast between her loss as a mother of a child who dealt with mental illness and loss due to death:

I**t's an ambiguous loss because you've lost the person that was there**. From [my son]'s grade school class, there was another family where the father had died of a heart attack and then the mother and the only child there, the daughter was killed in a terrible traffic accident when she was about 16 and the mother was in the car as a passenger and went through extreme injury and has recovered and of course, there was this extreme outpouring of love and support and you know, all of, she's almost seen as a heroine. Whereas, you know, I think people run away from mental illness. In NAMI people talk about **if you break your leg people will bring you a lot of presents and help you, where if you go the psych unit, often there is not that kind of outpouring.** And certainly with [my son]'s illness and the paranoia, he is not asking for people to come and help him, he's suspicious of them. But I would say even as a family member, the kind of support you get is different. **It's kind of a lonely journey**, and I think the stigma has a lot to do with it. Um, you know, and then about that ambiguous loss, that there's that initial seeing what's wrong, and one other point about that, both years when [my son] got progressively more mean to me, once I understood what kind of illness he had that kind of anger dropped away, that I understood it. And then there's the going to other people's graduations and weddings and baby showers, ect., it's ah, it's, **the grief is kind of reawakened**. Even if you don't try to wallow in it, it's still there. You know, to be realistic, to keep my heart open, um, to you know, to not hate myself or go into depression about well my life is, my life is unsuccessful because my child is disabled, because, my child is not a big success according to the norms, or that because I can't brag about my child's career or this or that, I can brag about what an outstanding student he was

> and he did well, in college and so forth, but you know, I'm not holding on to those things, I want to be present with how things are now. But anyway yeah, **I would just say that different moments of life can bring up that grief again. Because it's an ongoing loss, and that because I see my son's dream.**

Theme: Lost Dreams

"Seeing [her] son's dream" or opportunity loss was another common theme in the narratives of mothers' loss. The opportunity loss is not only the loss of educational and occupational possibilities for some individuals, but also a sense of lost opportunity for relationships. Emma describes her son's opportunity loss:

> Um, but he's what, **he's well aware that he was on a path towards, you know, what people would call a successful and happy life**, a quite engaging career path, making a lot of money, he was quite interested in that, having a wife and children. He wants that even though he never really understood how to create a relationship or really have a friend. He talks about that, wanting a wife and many children. He spends time designing, you know, the house that he would like to live in with them. The house that he'll build when, you know now he talks about winning the lottery because he feels like sort of a wasted person in society, that **he will never make the money he wanted to make**, so his only hope for making the money is winning the lottery, so he buys, I don't know, four chances each week on the Powerball. More recently, he started saying well maybe that isn't going to work out and he tries to think of some other thing, and you know **it's a grief for me, thinking that this happy successful child isn't there anymore…**

Ada echoed that: “So it was really frustrating and really emotional, seeing my child who had so much potential, have it all, **wash away**.”

Theme: Why is this Entity Here?

Mothers presented a number of explanations for why their children dealt with mental illness. Reasons presented included: genetics, parenting, drug use, environmental triggers, prenatal influences and “evil in the world.” None of the mothers presented those explanations in absolute terms; most presented them as questions or possibilities. Kathleen’s response was characteristic of the uncertainty regarding etiology most mothers presented:

> Well you work with, but I think that within the field**, there’s more and more known about these kind of things and it’s a real conundrum**. How much is biological, how much can be addressed through nutrition, diet, exercise, how much is the mind-body connection, how much is mental attitude, how much is genetics, how much can be ameliorated through drug therapy or other kinds of therapies?

Marilyn wondered if she had done something during the pregnancy that caused her son’s mental illness:

> Like I said, you’ve personally you know sometimes **I feel that it’s my fault or you put the blame on myself** because you know, I think did I do something when I was pregnant with him that caused it?

Ivy discussed inaccurate feedback from people around her daughter as related to the onset of her daughter's eating disorder. Interestingly, while she discusses it she uses in terms that indicate uncertainty:

> There's some, you know, **maybe** they were okay in some isolated little utopia, those triggers wouldn't go off. That trigger, the depression, or trigger the, the self, um sense of self-worthlessness. All of those things. **Maybe** those wouldn't happen. **Maybe** the need to be so ungodly thin. **Maybe** those things wouldn't happen if you could isolate your children. But, I don't believe that either. But they're just so unsure of themselves, that **the only image they get of themselves is from those people around them.** And it's a fun house, with those bad mirrors.

Marilyn spoke about her uncertainty about why her son's "brain misfired:" "…To me, **it's still really a mystery**. How the brain can just misfire, like it does."

Metaphor: Hope, Faith and Journey

Metaphorical analysis was used to explore hope. Mothers of children who dealt with mental illness spoke about hopes in terms of contexts of meaning and as a journey. A common context for hope was religious frameworks for why bad things happen in the world. Hope grounded in religion, as described by the mothers interviewed in this study, did not emphasize the specifics of why their particular child dealt with any particular mental illness; instead hope grounded in religion appeared to be related with being present with the reality of the situation.

Kathleen spoke of her Christian hope as one that compelled her to both acknowledge and "deal with" her children's mental illness:

> And I think as Christians**, we're not encouraged to deny reality and just push bad things away, but to say evil exists**. Bad things happen. How we going to deal with it?

Emma found hope through her Buddhist faith:

> I have a spiritual community and I think that's really important to mention. I actually practice Buddhist mediation and I have for many years and ah, you know, the basic practice is opening to things as they are. **Can I be present to things as they are? Can I be open to things as they are?** And I really think my long term practice **helped me to be able to open up to the fact**, in a few months rather than maybe taking the rest of my life, that my son has a really serious, devastating mental illness that destroys many of the personality aspects that were there before. This is a true, brain-based disability, he doesn't have all the capacities he once had and his life is going to look very different than what his original hopes once were. **It's that balance, being realistic, being with him, and having an open heart to him and his suffering**. So having him in my life often brings pain to me, either when he brings pain against me with either the critical or the delusional thinking about what he thinks I've done against him. And then also feeling his pain when he feels how worthless, a person with schizophrenia is typically seen unless by people in helping professions or I would think, people who have a spiritual basis for seeing value in every person or in every human life. But you know, if you go by the competitive

> values of so-called success: are you competitive, can you get a job. Our society is very, very competitive and **according to that model of reality, he's on the bottom rung**. And so, he feels that pain. And at times feels, like there's no point in his life. Um, I don't, I don't know if he would, it doesn't feel to me like he gets into, the kind of depression that you think of, like a mood disorder depression, he doesn't really exhibit mood symptoms, but he can be really sad or depressing. And you know, **a part of what he says is very realistic. It's not the whole truth, but it's a part of how things are.** Yeah, so I would say, I would say, I guess its part of my spiritual journey, is the fact that this has happened in my life.

Hope grounded in religion or spirituality was not only associated with being present with both the good and the bad in life. It was also described in terms of intercession. Ivy described a change in her religious beliefs that exemplifies this:

> I had to really reassess, as weird as this sounds, I had to really reassess my faith too. I was a practicing Catholic and I did not, um, find strength from that. I found that I had to kind of, sort of **really develop my own sort of faith**. I'm still a really strong believer in God, but it's my God; that might be a selfish thing, but I think that might be one of the biggest changes for me. I think I really, I, there's a line in a play, *Shadowlands*, that talks about praying when his wife is dying, one of the priests tells him he should pray, and he says "I pray every day, breathing in and breathing out, my entire life is a prayer." That's how I felt. I felt like I needed to be constantly hooked up with God**, I needed an IV prayer chain**. It was, "please let them come home safe, please let them come through the day, please let her not die because she

> is starving herself to death." I mean, it's just a constant. Constant. **It's not defined by rituals of going to church or meeting in Bible study or receiving communion, it is hook my up with a direct line.** And so, I can spend most of my day in contact with that Higher Power that's going to help me and help my kids. Because sometimes, that's all you have is that. So, that changed for me. I feel, like I'm maybe a better person for that? And that's okay. It's okay.

Brenda's description of hope also reflected intercession. She described gratitude related to a belief in angels that gave her faith that her children would be safe: "I'm thankful. I believe in guardian angels I guess, and I believe, and that's a big help. And **they go with our loved ones** when they need it."

Hope did not just exist on a metaphysical level. Hope was also for day-to-day behavioral change. Glenda described finding hope in small things:

> "Notice the small things, the small things in their behavior, **maybe they stopped reading and one day they pick the newspaper**… I think people they expect big changes at once. That doesn't happen at once."

Emma described seeing progress and finding hope in her son's consistency in completing lawn work:

> "**I guess that would be summer of 09, he took it upon himself to mow my lawn, and he was very consistent about it. And the summer before that he couldn't have, I know he couldn't have been consistent.** He would occasionally have to ask for help for something to do it, and I know he won't mow nice lawns all summer

> for 09 and we, I think that winter, last winter we shoveled snow together and I paid him for the time he spent shoveling snow and this summer he mowed my lawn all summer and he also mowed the lawn for a friend of mine who paid him very well."

Marilyn also described hope as related to productivity: "I'd say he's probably not a 100%, but I think with ah, I think **he's got strong possibility to be very productive.**"

Emma grounded hope in the context of typical outcomes for people with her son's disorder: "I can say **within the parameters** of having this really devastating condition, **he is doing really, pretty well**."

Hope was also grounded in the possibility of relapse:

> "I have no doubt that **we'll be able to get through it because we have gone through it** and other than the worse case scenario and I know that we would have the resources, and we would know who to call." (Marilyn)

The future-orientation of hope was evidenced in the number of traveling metaphors mothers used when describing their experience with their children's mental illness. A number of mothers described their experience as a "journey:"

> "It's been a **journey** up and down… You go two steps forward and a step backwards, you know." (Brenda)

> "Ah, it's been **quite a journey**, um. This, and it started about two and a half years ago, well actually it will be three years this December. I just pulled out some of my diary notes because, it was really intense in the beginning and it's been, everything's been really stable, the past year or so. It's kind of a, have to say right now

> everything's going well. I don't know, it was, definitely a **rollercoaster**. We just felt like it was **taking one step forward** and feeling like you might be on to something and then you know have it, kinda fall back and fall apart." (Marilyn)

> "[It's been] **A long haul**. From beginning to end." (Ada)

In terms of that journey, Nancy stressed the importance of going on, in spite of the hardships that occurred on the road:

> "I guess I was kinda the strong one because I had to be there for my mother, cause I'm all she had, so I had to be there to take care of her, so I had to keep my wits about me. I couldn't just give up, because, then nobody would be there to take care of her then. So I kinda kept her going too. **You got to go on**, we have responsibilities, I said you can't lose your job over this, you have to get your shit together and be strong because you have to go to work, you can't lose everything just because [my daughter was] having her problems… just knowing that **you can't give up**, I mean you got a whole life you live, **you can't just lay there and die. You have to go on** and be strong, so **life goes on** and you have to deal with what you get."

When it came to that road, however, Ida stressed that everyone is entering uncharted territory:

> "**There is no roadmap**, even though you think there's a roadmap, even though everyone else does something a certain way, it might not work with your child. So, every one of these cases is, has to be figured out individually."

In another type of future-oriented hope, Marilyn described the act of hoping as engaged closely with advocacy:

> "Never give up hope. **It'll always get better**. And you know, just ah, we need to stick together and work the system and if you're not getting what you want from the system, go to the top, go to the people at the top that are responsible. **But it is more hopeful today**. The medicines are better and ah, we're in a real tough economic time, so the money's not there, but we've always had to fight for the money anyway, but it is tough right now. But, I know a lot of people that are, have gone through it and they've survived and are doing well. Adults with the illnesses are doing well. And people need to know that, that there is hope, and that people will survive and that if we can stick by them, you know, **through** the tough times."

Summary

All of the mothers I spoke with discussed mental illness as an entity that exists independently of their child. The ways that they described that entity differed in terms of how changeable, adaptable or malevolent the entity was. Additionally, all of the mothers spoke about mental illness in terms of its affective elements. Those elements included devastation, confusion and cut-off. Mothers rarely expected mental illness when it emerged and most of them described a sense of numbness immediately following diagnosis. As time went on, mothers began to work with a new normal. While the grief and loss associated with raising a child who dealt with a mental illness didn't ever seem to dissipate entirely, hope was maintained through meaning structures, such as faith systems and beliefs about etiology, and action, such as advocacy. Use of the journey metaphor is useful for mothers of children who deal with mental illness because it implies both that current circumstances are passing and that there is movement toward a destination. Even if the particulars of that destination are unknown, trust that it is there and a part of the future may provide space for dreaming about what that destination could hold. Additionally, hope as a journey makes hope into an active process; one cannot progress on their journey if they are "just sitting there." Given the importance of "keeping on going" throughout the mothers' stories, emphasizing movement as productive and purposeful would be an important element of maintaining both self-concept, as an efficacious person, and hope.

Chapter V: Discussion

“We reject stigma in ourselves and others.” (National Alliance on Mental Illness, Principles of Support)

I began this research curious about the stories significant others had to tell about loving someone with a mental illness. Research I had read emphasized facts and figures, and only rarely emphasized the lived experiences of individuals who deal with it, let alone the experiences of loved ones. As a child of someone who deals with a mental illness and a professional who has worked with families and mental illnesses, I wanted to write that unwritten, but certainly non-fictional, story. While aspects of it existed in the current research literature, a holistic purview of mothers’ experiences of their children’s mental illness was absent.

This holistic study reflects much of what was found in earlier research. Namely, stigma and grief and loss were central to many of the mothers’ narratives of mental illness. Interestingly, stigma seemed to operate in a covert fashion. Rarely did a mother say that others thought less of her because she had a child who dealt with a mental illness; instead, many mothers spoke about mental illness as something secret, explosive or scandalous. The absence of overt naming of external stigma was something that seemed to indicate the power of its presence. While external stigma was not named, its effects were described in detail.

Grief and loss were also central to many of the mothers’ narratives. Unlike death, however, the grief and loss associated with raising a child who deals with a mental illness were unending and inconsistent. Mothers talked about loving their children and seeing the mental illness as something that “wasn’t them.” They talked about “fighting against” or “being strategic with” it. They also talked about their children “coming home to themselves.” Mental illness changed things and grief and loss were often a part of that change. At the same time, seeing the mental illness as an entity apart from their children seemed to allow room for loving both the child that was and the child that is, while maintaining an active hope. Interestingly, there did not seem to be any clear connections between the use of fixed or fluid metaphors compared to time since diagnosis or current stability.

Mothers’ experiences of their children’s mental illness were described in terms of changes in behaviors, feelings, expectations and hopes. Raising and parenting a child who deals with a mental illness changes the way one experiences the world. When a mother finds out about her child dealing with mental health issues, she is forced to confront the dreams that she had for her children and herself and accommodate to a new reality. Eventually, many mothers construct a “new normal.”

The “new normal” mothers construct is often hopeful, but the hopes mothers have are rarely for total recovery from the mental illness. More often than not, hope is for today and for small steps toward productivity or relationships. It may be simply the hope to keep on going in the midst of a long journey. These small, necessary hopes are the bread and butter of recovery when recovery is defined as the reconstruction of normal in a new reality.

Design Choices: Strengths and Limitations

Design choices of this research study reflect both strengths and limitations. As a qualitative study, the results are not generalizable. Since only mothers were interviewed, it cannot be assumed that fathers have had similar experiences. Additionally, as participants were recruited from the Midwestern United States, it cannot be assumed that a mother in a different part of the United States would have a similar experience. Since demographic data on race or ethnicity, income or age were not collected, the study's application to individuals from various races or ethnicities, income levels or ages cannot be assumed. Because the diagnoses in this study are not specifically identified, it cannot be known to what degree these results fit various DSM diagnoses. That said, describing mental illness as an entity may be common for mothers of children who deal with mental illness. Exploring the specificities of the metaphors loved ones use while describing a mental illness may be indicative of their preferred methods of coping or conceptualizations of the mental illness. For example, a mother who described "fighting against" a mental illness may prefer more active interventions to deal with the symptoms than a mother who described "noticing" a mental illness. While the results from this study are not generalizable, the depth to which I was able to explore participants' stories is a strength of it. Quantitative research, though generalizable, would not have been able to generate the same rich and thick descriptions used throughout this study.

Another design choice was that a single researcher, with extensive prior knowledge of mental illness and family dynamics, conducted all of the interviews. This design choice could be viewed as a limitation of the study because I approached the interviews with preconceived ideas and opinions. Those ideas and opinions were reflected in the standard interview questions and follow-up questions asked during the interviews. The potentially limiting effects of this design choice, however, were minimized through the use of auditors and peer debriefers, and through the process of researcher reflexivity (Johnson, 1997). Through both of those resources, alternative explanations were explored. Additionally, my own experience as a family member of someone who deals with mental illness, and as a mental health worker, contributed to “adequateness of knowing” and may have enhanced the study by giving me an insider perspective on how families experience mental illness, and increased attunement to participants’ realities.

Plenty of time was allowed for mothers to express their experience and all were invited to add any follow-up comments after the interview via email or telephone. Allowing follow-up questions was a strength of this study, as it allowed me to clarify abstract concepts and descriptions. For instance, a number of mothers described their experience as “hard.” I followed up by asking “What is hard about it?” and each of the mothers had different responses. Allowing for follow-up questions enabled the final product of this research to include nuanced descriptions of mental illness.

The range of time since diagnosis is both a strength and a weakness of this study. Although data on mothers’ specific ages were not collected, the children discussed in the interviews had a wide range in age and in time since receiving diagnosis. Some participants reported that their child had begun demonstrating mental health issues within the past year and others reported that they had been dealing with mental health issues for over thirty years. The range of time since onset of illness is a strength of the study because it follows that coping and the construction of meaning would change over time. A number of snapshots of participants' experiences of mental illness were presented in this study. The inconsistency in time since diagnosis may be a limitation to this study because it may reflect loss of details and hindsight bias. This study could have been strengthened by systemically tracking the time since diagnosis for each participant.

Further Research

Future research is needed. Specifically, future studies should include more demographic data to determine if individuals from different ethnic, racial or generational cohorts more commonly utilize different types of metaphors. Studies that focus on the experience of specific diagnoses need also be conducted in order to look for similarities and differences across different types of mental illness. Studies should also focus more on fathers and families formed through assistive reproductive technologies and adoption. Larger studies that involve qualitative and metaphorical analysis are needed to triangulate the findings found in this research.

Regarding metaphorical research, future work should also focus on whether or not fluid or fixed metaphors predominate narratives on the basis of time since diagnosis or whether or not an individual was currently experiencing an episode of mental illness.

Conclusions

This study contributes to existing research by exploring and analyzing metaphorical language mothers use with regard to mental illness and hope. It also contributes to understanding some of the emotional responses mothers may have to their children's mental illness. Additionally, by highlighting metaphor as used by mothers of children who deal with mental illness, this study emphasizes the importance of the abstract, spiritual and meaning-based structures that frame experiences of mental illness. Anticipating, exploring and understanding the abstract elements of an individual's experience with mental illness may promote therapeutic alliance, and thusly, would improve treatment outcomes. By including another family member (in this case, mothers), this study also contributes toward development of a systemic conceptualization of mental illness.

There is an element of dealing with a mental illness, either individually or systemically, which seems to compel secrecy and silence. I know that in my personal experience, talking about mental illness as experienced by my family or loved ones have often felt risky. To say something about it risked being known or judged or reduced to a caricature. While I might have named stigma, I do not think that prior to completing this study I would have recognized just how pervasive stigma is, Mothers' stories seemed to align with my own, in that external stigma was rarely named but was instead described in terms of self-blame, loneliness and cut-off. Both individuals and families of those that deal with mental illness have been silenced by shame and stigma. By normalizing and giving voice to the changed realities that affect everyone who deals with mental illness, professionals and policy makers pry stigma's silencing palm from the mouths of those who deal with it. Normalizing and giving voice to those changed realities also allows for individuals who have been previously disenfranchised and cut-off from community to unite with each other. In reconnecting with the voices of the silenced, authentic hope is rebuilt on reliable ground.

References

Abrams, M.S. (2009). The well sibling: Challenges and possibilities. *American Journal of Psychotherapy, 63*(4), 305-317.

American Psychiatric Association (2000). Diagnostic and statistical manual of mental disorders (text revision). Washington, DC: American Psychiatric Association.

Bishop, P., Cliverd, A., Cooklin, A., & Hunt, U. (2002). Mental health matters: a multi-family framework for mental health intervention. *Journal of Family Therapy, 24,* 31-45.

Bland, R., & Darlington, Y. (2002). The nature and sources of hope: Perspectives of family caregivers of people with serious mental illness. *Perspectives in Psychiatric Care, 38*(2), 61-68.

Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief.* Harvard University Press: Cambridge, MA.

Boursnell, M. (2007). The silent parent: Developing knowledge about the experiences of parents with mental illness. *Child Care in Practice, 13*(3), 251-260.

Bowland, S., Hensely, M., Johnson, B., & Fleming, A. (2010). Consumer focus groups:

A key to transforming behavioral health systems?, *International Journal of Mental Health (39)*1, 16-28.

Burkhalter, T. (2010). Writing for special needs: The importance of the real relationship. *Psycho-analytic Psychotherapy in South Africa, 18*(1), 20-39.

Chang, K.H., & Horrocks, S. (2006). Lived experiences of family caregivers of mentally ill relatives. *Issues and Innovations in Nursing Practice,* 435-443.

Clarke, D.E., Dusome, D., Hughes, L. (2007). Emergency department from the mental health client's perspective. *International Journal of Mental Health Nursing, 16,* 126-131.

Corrigan, P.W., Miller, F.E., & Watson, A.C. (2006). Blame, shame and contamination: The impact of mental illness and drug dependence stigma on family members. *Journal of Family Psychology, 20*(2), 239-246.

Corring, D.J. (2002). Quality of life: Perspectives of people with mental illnesses and family members. *Psychiatric Rehabilitation Journal, 25*(4), 350-358.

Cowling, V., Edan, V., Cuff, R., Armitage, P., & Herszberg, D. (2006). Mental health consumer and carer participation in professional education: 'Getting there together' for children of parents with mental illness and their families. *Austrailian*

Social work, 59(4), 406-421.

Creswell, J. W. (2009). Research design: Qualitative, quantitative and mixed methods approaches. (3rd ed.) Sage Publications: Thousand Oaks, CA.

Dickstein, S., Seifer, R., Haden, L.C., Schiller, M., Sameroff, A.J., Keitner, G., & et.al. (1998). Levels of family assessment: II. Impact of maternal psychopathology on family functioning. *Journal of Family Psychology, 12*(1), 23-40.

Dixon, L., Luckstead, A., Stewart, B., Burland, J., Brown, C.H., Postrado, L., McGuire, C., & Hoffman, M. (2004). Outcomes of the peer-taught 12-week family-to family education program for severe mental illness. *Acta Psychiatrica Scandinavica, 109*, 207-215.

Drapalski, A.L., Leith, J., Dixon, L. (2009). Involving families in the care of persons with schizophrenia and other serious mental illnesses: History, evidence, and recommendations. *Clinical Schizophrenia & Related Psychoses*, 39-49.

Endrawes, G., O'Brien, L., & Wilkes, L. (2007). Egyptian families caring for a relative with mental illness: A hermeneutic study. *International Journal of Mental Health Nursing, 16*, 431-440.

Feldman, D.B., Crandall, C.S. (2007). Dimensions of mental illness stigma: What about mental illness causes social rejection? *Journal of Social and Clinical Psychology, 26*(2), 137-154.

Ferris, P.A., & Marshall, C.A. (1987). A model project for families of the chronically mentally ill. *Social Work,* 110-114.

Finke, L.F. (2004). Families: The forgotten resource for individuals with mental illness. *Journal of Child and Psychiatric Nursing, 17*(1), 3-4.

Heru, A.M. (2000). Family functioning, burden, and reward in the caregiving for chronic mental illness. *Families, Systems & Health, 18*(1), 91-103.

Haslam, D., Haggarty, J., McAuley, L., Lehto, J., Takhar, J. (2006). Collaboration in action: Maintaining and enhancing shared care relationships through the TIPP clinical model. *Families, Systems & Health, 24*(4), 481-486.

Fudge, E.A. & Robinson, P. (2009). A public health approach to promoting better mental health outcomes for children of parents with a psychiatric disability. *Psychiatric Rehabilitation Journal, 33*(2), 83-90.

Furman, R., & Shukraft, A. (2007). A qualitative study of letters to President Kennedy from persons with mental illness and their families: Using the research poem in policy orientated research. *Journal of Sociology & Social Welfare, 34*(4), 81-95.

Gerson, R. Davidson, L., Booty, A., McGlashan, T., Malespina, D., Pincus, H.A., et al. (2009). Families' experience with seeking treatment for recent-onset psychosis. *Psychiatric Services. 60*(2). 812.

Getty, C., Perese, E., & Knab, S. (1998). Capacity for self-care of persons with mental illnesses living in community residences and the ability of their surrogate families to perform health care functions. *Issues in Mental Health Nursing, 19*, 53-70.

Gibson, R.C., Abel, W.D., White, S., & Hickling, F.W. (2008). Internalizing stigma associated with mental illness: Findings from a general population survey in Jamaica. *Revista Panamericana de Salud Publica, 23*(1), 26-33.

Godress, J., Ozgul, S., Owen, C., & Foley-Evans, L. (2005). Grief experiences of parents whose children suffer from mental illness. *Australian and New Zealand Journal of Psychiatry, 39*, 88-94.

Hinshaw, S. (2005). The stigmatization of mental illness in children and parents: Developmental issues, family concerns, and research needs. *Journal of Child Psychology and Psychiatry, 46*(7), 714-734.

Hoadgwood, K.E. (2005). Family-based services in children’s mental health: A research review and synthesis. *Journal of Child Psychology and Psychiatry, 46*(7), 690-713.

Hoffman, D., & Rosenheck, R. (2001). Homeless mothers with severe mental illnesses and their children: Predictors of family reunification. *Psychiatric Rehabilitation Journal, 25*(2), 165-169.

Hooley, J.M. (2004). Do psychiatric patients do better clinically if they live with certain kinds of families? *American Psychological Society, 13*(5), 202-205.

Johnson, R.B. (1997). Examining the validity structure of qualitative research. *Education, 118*(2), 282-292.

Jones, K. (2009). Addressing the needs for carers during early psychosis. *Early Intervention in Psychiatry, 3*, 522-526.

Kawanishi, Y. (2005). The process of causal attribution and interpretation of the mental illness by the patients' family members in the United States and Japan. *International Journal of Mental Health, 33*(4), 19-34.

Kessler, M.L., Ackerson, B.J. (2004). Wraparound services: An effective intervention for families impacted by severe mental illness. *Journal of Family Social Work, 8*(4), 29-45.

Lakoff, G. (1993). The contemporary theory of metaphor. In Ortony, A (Ed.), *Metaphor and Thought* (pp. 202-251). New York, NY: Cambridge University Press.

Ludbrook, C., & Hafner, R.J. (1998). The positive family contribution of those with serious mental illness. *Journal of Clinical Psychology, 54*(4), 501-507.

Marshall, A., Bell, J.M., Moules, N.J. (2010). Beliefs, suffering, and healing: A clinical practice model for families experiencing mental illness. *Perspectives in Psychiatric Care, 46*(3), 197-208.

Marshall, T., Solomon, P., Steber, S., Mannion, E. (2003). Provider and family beliefs regarding the causes of severe mental illness. *Psychiatric Quarterly, 74*(3), 223-236.

Minkler, M. (2004). Community-based research partnerships: Challenges and opportunities. *Journal of Urban Health, 82*(2).

Office of the Surgeon General, (1997). Mental health: A report of the Surgeon General. Retrieved April 4, 2011, from http://www.surgeongeneral.gov/library/mentalhealth/chapter2/sec2_1.html.

Rudden, M.G. (2009) Helping children through a parent's deployment: preventing the intergenerational transmission of trauma. *The Exceptional Parent. 39*(5). 89-91.

Smithgall, C., Mason, S., Michels, L. & et. Al (2009) Intergenerational and interconnected: mental health and well-being in grandparent caregiver families.

Families in Society. *90*(2). 167-175.

Suresky, M.J., Zauszniewski, J.A., & Bekhet, A.K. (2008). Sense of coherence and quality of life in women family members of the seriously mentally ill. *Issues in Mental Health Nursing, 29*, 265-278.

Wahl, O.F. (1995). Media madness: public images of mental illness. Rutgers University Press.

Ward, E.C., & Heidrich, S.M. (2009). African American women's beliefs about mental illness, stigma and preferred coping behaviors. *Research in Nursing & Health, 32*, 480-492.

Wisdom, J.P., Bruce, K., Saedi, G., Weis, T., & Green, C.A. (2008). 'Stealing me from myself': Identity and recovery in personal accounts of mental illness. *Australian and New Zealand Journal of Psychiatry, 42*, 489-495.

Wong, C., Davidson, L., Anglin, D., Link, B., Gerson, R., Malaspina, D., & et. al. (2009). Stigma in families of individuals in early stages of psychotic illness: family stigma and early psychosis. *Early Intervention in Psychiatry, 3,* 108-115.

Wynaden, D. (2007). The experience of caring for a person with a mental illness: A grounded theory study. *International Journal of Mental Health Nursing, 16*, 381-

389.

Young, J., Bailey, G., & Rycroft, P. (2004). Family grief and mental health: A systemic, contextual and compassionate analysis. *Australian & New Zealand Journal of Family Therapy, 25*(4), 188-197.

Yun-Hee, J., Brodaty, H., & Chesterson, J. (2004). Respite care for caregivers and people with severe mental illness: Literature review. *Journal of Advanced Nursing, 49*(3), 297-306.

Appendix A: Informed Consent

Title: Meaning Making and Coping among Parents of Youth Dealing with Mental Illness

Investigator:	Research Sponsor
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Hello,

I am a Masters student in Marriage and Family Therapy at the University of Wisconsin – Stout. I am doing research on how parents think about their experience after their older child is diagnosed with a mental illness. I am in also interested in how parents define and experience their strengths during stressful times. I will be finding out more about this by conducting and recording interviews at a time convenient to you.

Each interaction is expected to take 60 minutes, which will consist of a semi-structured interview. I will audio-record the whole interview.

Potential risks of participating in this project include:

Emotional stress
Psychological stress

Potential benefits of participating in this project include:

Increased awareness of your strengths as a parent
Promoting future research into the caregiver's experience when someone is diagnosed with a mental illness
Promoting future research that may improve treatment outcomes

Names and any identifying details associated with your contribution (your name or your child's, any other family member's) will not be included on any documents. I do not believe that you can be identified from this information. This informed consent will not be kept with any of the other documents completed with this project.

Your participation in this study is entirely voluntary. You may choose not to participate without any adverse consequences to you. Should you choose to participate and later wish to withdraw from the study, you may discontinue your participation at any time without incurring adverse consequences.

This study has been reviewed and approved by The University of Wisconsin-Stout's Institutional Review Board (IRB). The IRB has determined that this study meets the ethical obligations required by federal law and University policies. If you have questions or concerns regarding this study please contact the Investigator or Advisor. If you have any questions, concerns, or reports regarding your rights as a research subject, please contact the IRB Administrator.

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By signing this consent form, you agree to participate in the project entitled "Meaning Making and Coping among Parents of Youth Dealing with Mental Illness"

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Signature Date