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Parents Of Adolescent Children With Mental Illness: A Qualitative Exploration Of The Lived Experience

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PARENTS OF ADOLESCENT CHILDREN WITH MENTAL ILLNESS: A
QUALITATIVE EXPLORATION OF THE LIVED EXPERIENCE

by

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This dissertation, submitted by Lindsay Allyn Yates, in partial fulfillment of the requirements for the Degree of Doctor of Philosophy from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

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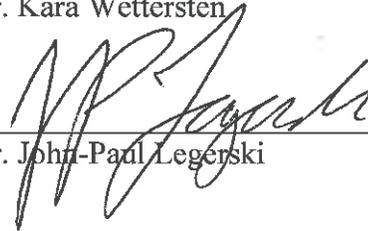
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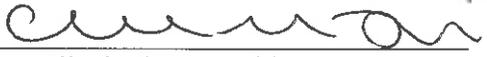
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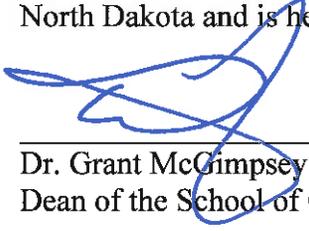
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Lindsay Allyn Yates
05/08/2017

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ABSTRACT

The current exploratory study aimed to understand the experience of parents whose children have severe and persistent mental illness. It was hypothesized that themes developed from parents' responses to interview questions would indicate the presence of a) grief, b) trauma, c) subjective burden, and d) objective burden. Participants were 13 parents, comprised of conveniently sampled biological parents and legal guardians. Each parent was independently interviewed using a semi-structured protocol. Interviews were audio recorded and transcribed by the principal investigator. Transcripts were analyzed using consensual qualitative analysis. An in-depth analysis of each transcript and cross analysis of transcripts yielded seven domains: Impacts; Evolving Behaviors, Feelings, and Attitudes; Relationships; Treatment Experiences; Understanding; Supports; and Barriers. Results indicated the presence of grief, trauma, subjective burden, and objective burden for all participants and therefore supported the hypothesis. This study suggests that parents of adolescents with severe and persistent mental illness may benefit from inclusion in their children's treatment planning and decision making as well as be offered support by way of individual and family therapy, community or online support groups, and have their reactions validated and normalized by mental health providers. Furthermore, future research should continue to explore the phenomenological

experience of parents of children and adolescents with severe mental illness in addition to

quantitatively measuring their grief, trauma, and burden symptoms.

Keywords: parents, severe mental illness, adolescents, CQR, grief, trauma, burden

CHAPTER I

INTRODUCTION

Parents of Adolescent Children with Mental Illness: A Qualitative Exploration of the Lived Experience

In the United States, almost one-fourth of adolescents meet the diagnostic criteria for a mental illness (Merikangas et al., 2010). Some of these adolescents living with mental illness remain in traditional classrooms and homes, while others and their diagnoses are hidden in residential treatment facilities, private or state-run community residences, or hospitals. Behind each of these children are caretakers. For those children not placed in out-of-home treatment facilities, many of the caretakers are parents. Many times, the identified child's mental illness cannot go completely unnoticed or untreated; even if unknown to or ignored by society, children and their mental health are acknowledged by parents and family, school faculty or staff, and mental health or medical providers. But the experiences of the identified patient's parents go largely unnoticed, especially the parental experience of loss and grief specifically related to their child's mental illness.

In November 2013, the people of the United States had little choice but to acknowledge one father's experience of living with and caring for a son with mental illness. The southeastern portion of the U.S., one particularly known for its lack of state-supported mental health care, was shocked to hear that Senator Creigh Deeds of Virginia had been brutally attacked and stabbed by his son, Gus. Gus, after attacking his father,

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found a loaded gun and shot himself. His struggle to live with bipolar disorder, diagnosed in 2011, ended on that fateful morning, just hours after Senator Deeds had brought his son to the local emergency room for fear that Gus would hurt himself or someone else. Resiliently, Senator Deeds urges the public to remember his son as a cheerful, humorous, intelligent young man, and attributes Gus's death to a failed health care system, not to his son who was living with mental illness.

For Senator Deeds, life with a mentally ill son ended prematurely; his loss and grief is now the product of the all-too-soon death of his son. For many parents, feelings of loss and grief are chronic. For those parents whose children live with mental illness, grief and loss is persistent (Penzo & Harvey, 2008; MacGregor, 1994). They grieve losing the child they once had and knew; the aspirations they had for their children; the support of friends, family, and other types of social support; the financial costs of taking care of their children; and a life without the threat of a sudden mental health crisis. In many ways, these parents are disenfranchised and are, of sorts, a hidden population. Not all parents of children with mental illness or who lose their child to the battle of mental illness make the national news. And not all parents frame their situation to attribute responsibility of mental illness, and consequently their feelings of loss and grief, to a failing mental health care system. The loss and grief experienced by parents with mentally ill children is not acknowledged, nor is it completely understood. Previous research has focused on the experiences of older-aged parents who still serve as caretakers for their adult children with severe and persistent mental illness. More recently, researchers have shifted their focus to examine younger parents of adolescent and pre-adolescent children with mental illness. Despite this shift, small sample sizes in

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research investigating parental experiences of caretaking for children with mental illness limit generalizability of results. Because of this, more research is needed to highlight parents' experiences in different settings, such as those living in a rural area.

History and Family Perspectives

Much of the formative literature concerning parents of children who were disabled has focused on parents of children who were born with medical illness, such as Down's syndrome (Gath, 1977; Schell, 1981). Schell (1981) asserted that parents' adjustment to their disabled child was influenced by three factors: severity of the handicap, internal familial supports, and supports outside of the family. The introduction of a new baby is an adjustment for all parents, but Schell (1981) stressed that the adjustment of a baby with medical abnormalities is especially complicated, depending particularly on when the abnormality is identified; specifically, whereas parents whose children are identified as disabled from birth are forced to alter their expectations for their child's development immediately, parents whose child is identified with abnormalities later in life face the obstacle after a period of time where the problem and cause is unknown.

No matter the timing, parents whose children are identified as handicapped struggle with confidence in themselves, the loss of the expectations for their child's development and future self, and even possible burnout and issues in relational attachment to their child (Schell, 1981). Reciprocity is the notion that relationships between infants and caregivers are reciprocal, meaning that the relationship between parent and child is an interaction and not strictly one of a parent creating a cause and an infant making a response (Lewis & Rosenblum, 1974; Thoman & Trotter, 1978).

However, if an infant is unable to respond or participate in the reciprocal relationship, it is thought that the developing bond will be vulnerable. This sort of fragile bond is thought to contribute to burnout in caregivers. Five types of burnout parents might experience are psychological, social, intellectual, psycho-emotional, and introspective (Hagen, 1981; Schell, 1981). Given the assertion that parents who have to adjust to a child who is born with an illness and are disposed to these types of burnout, it is important to further understand the process of adjustment of parents who find out about a child's illness later in life. In accordance, research is needed to see if these same types of burnout are applicable to those who are parents of a child who is diagnosed with a severe mental illness. Given that children with severe mental illnesses may be unable to participate in building attached relationships through reciprocity, attachment relationships in the parent-child dyad should be assessed. The parental experience should be explored, including how the attached relationship was created, has changed, is currently functioning, is expected to function, and how the relationship has been impacted, if at all, by the child's diagnosis of a severe mental illness.

In the proposed study, the purpose is to explore the parental experience of having a non-adult child with a severe mental illness, especially in relation to grief, traumatic reactions, and both subjective and objective burden. Given the elusiveness of parents in this particular situation, it is important to conceptualize and differentiate the constructs that compose their multifaceted experiences. Therefore, definitions for the constructs included in the proposed current study are listed here. Grief is defined as an emotional reaction to the loss of someone or something important and mourning is defined as the expression of grief (Meyers, 2000). Chronic sorrow is defined as the experience of

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unresolved grief associated with ongoing loss with no foreseeable end to the loss experience (Eakes, 1995). Trauma reactions are responses to an upsetting event characterized by emotional, cognitive, and physical reactions including avoidance behaviors, rumination or flashbacks, intrusive thoughts, hypervigilance, distress when faced with reminders of or a similar event, or a combination of these symptoms (Halpern & Tramontin, 2007). Burden as a whole can be deconstructed into two distinguished constructs: subjective burden and objective burden. Subjective burden is defined as a caregiver's perception of or emotional reactions to their experience. Objective burden is defined as the negative consequences of a situation that are experienced by a caregiver including loss of health, finances, and social support (Provencher & Mueser, 1997).

Grief

Although parents often experience ongoing grief concerning their children's mental illness, there has been little acknowledgment or treatment of these symptoms. MacGregor (1994) highlighted the importance of recognizing and appropriately addressing parents' grief related to the diagnosis of mental illness in their children. Characteristics of parental grief are believed to include the *avoidance* phase, the *confrontation* phase, and the *reestablishment* phase – avoidance during the initial months of diagnosis, confrontation of circumstances instigating emotions of anxiety and guilt, and finally finding emotional homeostasis in the reality of their ever-changed life (MacGregor, 1994). Of particular importance is also highlighting the avoidance phase, specifically sleeplessness and the internal worry parents experience that they are going crazy. Such reactions may verge on those similar to traumatic reactions, with losing sleep

due to replaying events or ruminating on worries. Further research is needed to parse normal avoidance phase reactions of grief from those of traumatic reactions.

Grief is experienced in cycles perpetuated by crises such as stressful events, health crises, and unmet developmental milestone. More specifically, parents who experienced loss in mental illness of a child were described to experience personal, internal, existential, and societal losses. Personal losses include the loss of a child's personality, role in family and society, potential future, potential talents, and relationship with the parent. Internal losses include factors such as loss of spiritual beliefs, loss of parental competence, loss of security and faith in the world, and loss of hope for dreams of the future. Some external, felt losses include loss of family and social support, financial resources, privacy, and a predictable family system. Existential loss involves parents' loss of their cognitive schemata of how the world works in order to integrate meaning of their child's mental illness into their belief system. Socially, parents of children with severe mental illness can often feel distanced, separated, isolated, and unaccepted, partly because this type of loss is not validated or fully visible to society and also because this type of loss has been deemed unusual and stigmatizing by American culture (MacGregor, 1994).

Notably, these parents may experience grief not recognized or validated by society, and this lack of recognition may be a barrier to parents grieving in a healthy manner (MacGregor, 1994). The author asserts that mental health professionals may pathologize the reactions of these parents, another count of invalidation and lack of support experienced by these parents. It seems as if practitioners might be recognizing grief symptoms in parents but are wrongly assessing and labeling these symptoms.

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Therefore, it is important to learn more about the prevalence of grief in these parents, how it is expressed internally and externally, and how it can be acknowledged and validated instead of pathologized and stigmatized, especially by mental health practitioners (MacGregor, 1994).

For many, the distinction between grief and mourning is unclear and, therefore, unacknowledged (Meyers, 2000). Despite its importance, it is even more unacknowledged in the context of those who mourn and grieve the mental illness of a child. Meyers (2000) highlighted the importance of grief and mourning related to mental illness. She explained the difference between grief, the reaction to losing someone or something valued, and mourning, the expression of grief. She discussed the stages of grief a family member may experience: *shock and disbelief*, *suffering*, and *recovery or reconciling* the loss. Meyers believes that family members begin the grieving process as soon as a mental illness is diagnosed in their loved one. The grieving process may be easier for family members who utilize support groups or attend programming. Included in the discussion was secondary losses, such as parents' own grief for themselves – along with the grief for their child and the losses the child has will suffer – including a loss of dreams for the future, loss of friend and family support, a loss of dignity and self-esteem, and loss of personal health. Lastly, parents were urged to find acceptance by learning and practicing advocacy and breaking stigma by attending community support groups (Meyers, 2000). Highlighting losses and secondary losses are important, as certain losses may be perceived as or actually are more fixable than others. It is important to understand the grief experiences of parents, especially those beginning immediately at the diagnosis of the child, so that clinicians working with families, and especially those delivering the

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news of a mental diagnosis, can identify and address grief symptoms in caretaking parents.

One of the most well known models of grieving was created by Kubler-Ross (1969) when describing stages of grief in relation to death and dying. Penzo and Harvey (2008) discussed the application of Kubler-Ross's (1969) stages of grieving – denial, anger, bargaining, depression, and acceptance – to parents of children with mental illness. Penzo wrote about this application from both her perspective as a licensed clinical social worker and as the mother of a daughter with a severe mental illness. Her daughter has lived with mental illness for over a decade; she was first hospitalized at the age of 10 years and has resided in both state and private residential facilities since the age of 13 years because of her suicidal tendencies and impulsivity. The authors purport that parents of children with mental illness experience the stages of grief (Kubler-Ross, 1969) in cycles rather than in a linear fashion; families who experience a death experience their loss and grief once, whereas families living with a loved one with a mental illness experience a crisis and then the stages of grief, and this is repeated each time a crisis is experienced. Types of crises include a severe psychiatric emergency or a major developmental milestone not being met due to the child's illness. Another type of trigger is a crisis – of their child or of their child's peer – in a psychiatric facility, as witnessing other children's crises may remind parents of their own child's fragility to mental illness symptoms (Penzo & Harvey, 2008). It should be noted that these types of crises may contribute to traumatic reactions, as these crises are characterized by threats of or actual self-harm, suicide, or violence towards others. Given these experiences, it would be useful to explore if reactions that have been characterized as grief in the past are actually

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better characterized as symptoms of a traumatic reaction, or compounded traumatic reactions.

Penzo and Harvey (2008) discussed implications for social workers working with parents of children with mental illness and that building an effective working relationship is dependent on empathy for the parents combined with the provision of emotional support. Because mental health crises may arise seemingly out of nowhere, it is imperative that parents' grief reactions be acknowledged, normalized, and addressed. However, this cannot happen until grief reactions are better understood and information about parental grief is disseminated to mental health and general practitioners (Penzo & Harvey, 2008).

The Experience of Parents with Adult Children with Severe and Persistent Mental Illness (SPMI)

Richardson, Cobham, Murray, and McDermott (2011) reviewed extant studies that explored grief in parent and family member caregivers of adult children with severe mental illness. Past research was reviewed to highlight evidence for the relationship between caregivers' grief and other outcomes. For the purposes of the following section, grief should be distinguished from chronic sorrow. Whereas grief is an emotional reaction to the loss of someone or something important, chronic sorrow is defined as the experience of unresolved grief associated with ongoing loss with no foreseeable end to the loss experience (Eakes, 1995). Research that focused on predicting grief in parents of adult children with severe psychopathology was highlighted. A search for peer-reviewed papers focused on grief and loss in parents from the past 175 years yielded 12 studies that were included in this review. Some studies also included non-parental family members in

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their study. Studies ranged in number of participants from four to 225, while one-fourth of studies only sampled parent dyads. Over half of the studies utilized a qualitative methodology, many collecting data by using unstructured or loosely structured interviews, while five utilized quantitative methodologies. Almost half of the studies required participants to be parents of adult children with schizophrenia, while one allowed participants to be parents of a child diagnosed with schizophrenia or schizoaffective disorder. A quarter of the reviewed studies targeted family members, mainly parents, of relatives with schizophrenia or bipolar, while another quarter of the studies extended the diagnosis criteria to include adult children with schizophrenia, bipolar disorder, major affective disorder, or a nonspecified mental illness diagnosis. Most study participants were White, were female, were middle class, were about 60 years old, and nine out of 10 respondents were parents and were recruited from community advertising, inpatient and outpatient settings, and support groups. The identified patient was typically male and about 30 years old. The majority of patients were diagnosed with schizophrenia, the duration of which was less than one year to more than 20 years (Atkinson, 1994; Davis & Schultz, 1998; Eakes, 1995; Godress, Ozgul, Owen, & Foley-Evans, 2005; Jones, 2002; Miller, Dworkin, Ward, & Barone, 1990; Mohr & Reagan-Kubinski, 2001; Osborne & Coyle, 2002; Ozgul, 2004; Solomon & Draine, 1996; Tuck, du Mont, Evans, & Shupe, 1997; Wiens & Daniluk, 2009).

Conclusions of the studies, collectively, were categorized into four groups (Richardson et al., 2011). Findings of qualitative studies ($n = 9$) provided descriptions of the loss and grief, and chronic sorrow, of parents and other family members of relatives with severe mental illness. The occurrence of grief in these parents and family members

was quantified using descriptive statistics ($n = 4$). Correlations between grief and different outcomes were analyzed. Then, predictive variables of parents' and family members' experience of grief were examined ($n = 3$). Lastly, advice for future research was given after considering methodological and theoretical flaws and successes of existent studies (Richardson et al., 2011).

Because few studies have focused on the impact of pre-adult children's mental illness on their parents, future studies should utilize parents of adolescent and pre-adolescent children diagnosed with severe mental illnesses. By shifting their focus to these parents, researchers may better gain access to parents' real-time experiences as mental illness manifests in their children; by accessing parents earlier and closer to the event of mental illness manifestation, researchers may gain a more accurate, more detailed, and less reminiscent version of parents' experiences. The demographics of the parental sample must be diversified, and longitudinal studies must be conducted. The researchers encouraged the exploration of identifying risk factors for parental grief (Richardson et al., 2011); along with this, they also recommended looking at resiliency factors among parents of children with mental illness who do not experience significant loss or grief symptoms.

Miller et al. (1990) pioneered the formal study of grief in family members of individuals diagnosed with severe and persistent mental illness. Until their study, there had been no appropriate quantitative instrument created to aid in studying the presence of grief in these family members, although such an instrument did exist to measure grief in family members who were surviving a deceased loved one. In order to further the study of grief for this specific population, the researchers adapted an existing instrument that

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measures grief among family members of a deceased person, the *Texas Revised Inventory of Grief* (*TRIG*; Faschingbauer, 1981), and created a new instrument to measure the grief among family members of a person with severe mental illness, the *Mental Illness Version of the Texas Inventory of Grief* (*MIV-TIG*; Miller et al., 1990). The *TRIG* (Faschingbauer, 1981) is a self-report measure consisting of three parts; the first measures the family member's initial reaction to the loss, the second measures the family member's current reaction to the loss, and the third addresses facts related to death. For their adaptation, researchers rephrased statements of the first and second parts to concern the loss related to a family member's mental health, and did not use the third part as it did not relate to their research intentions (Miller et al., 1990). Statements are responded to on a 5-point Likert scale ranging from completely false to completely true. In developing the *MIV-TIG* (Miller et al., 1990), the researchers aimed to assess if family members of someone with a mental illness experienced grief, if their adapted measure was statistically valid in measuring grief, if grief differed between family members of a patient with schizophrenia as compared to family members of a patient with bipolar disorder, and if they could find related or predictive familial factors associated with grief.

Family members of patients with schizophrenia or bipolar disorder were recruited for participation at either a psychoeducational workshop or from a support group (Miller et al., 1990). These participants were administered a demographics questionnaire and the *MIV-TIG*. The demographics questionnaire measured the diagnosis of the family member patient, how long the patient had been experiencing the illness, the age at which the participant was diagnosed, and the total number of hospitalizations the family member had experienced. A total of 58 family members were given the *MIV-TIG*, although 48

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fully completed the questionnaires. Of those initially sampled, 33 were family members of someone with schizophrenia and 25 were family members of someone with bipolar disorder. Close to half of the respondents of each subgroup were currently living with the diagnosed patient (Miller et al., 1990).

Results indicated that respondents did not show strong indications of grief when their past feelings were assessed, with the exception of having symptoms of difficulty sleeping and finding it hard to work in the initial months after their relatives' diagnosis (Miller et al., 1990). However, more items were endorsed to indicate more symptoms of grief when assessing respondents' current degree of grieving. Participants indicated they missed who their family member used to be and they had preoccupied thoughts of how the family member could be if it were not for their mental illness. Findings indicated no statistically significant differences in indications of present grief between the two subgroups, for family members living with the patient as compared to not living with the family member, and weak correlations were found for present grieving and patient characteristics such as number of hospitalizations, age when diagnosed, and length of illness. Lastly, the internal consistencies for both parts of the newly adapted scale were quite high (alpha coefficient = .824 and .92). Based on these results, Miller et al. (1990) were able to support the existence of grief in family members of a loved one with a severe mental illness and further asserted that this grief is comparable to the experience of grieving a deceased family member. However, these results support the notion that the grief experienced may differ for family members of a severely mentally ill person in that the reaction may be delayed or progress over time.

Parents have been shown to grieve the loss of their child to mental illness. This not only includes loss related to the most commonly thought of disorders, such as schizophrenia and bipolar disorder, but also to losing the essence of one's child – the personality – though traumatic brain injury. Atkinson (1994) aimed to compare symptoms of grief among three groups of parents; one group was comprised of parents of adult children with schizophrenia, the second group was composed of parents whose children had died, and the third was composed of parents whose children had experienced a head injury resulting in an organic personality disorder. Seventy-five parents, 25 in each group, completed self-report scales assessing grief, anxiety, depression, and substance abuse. To assess grief, the *MIV-TIG* (Miller et al., 1990) was used.

Results indicated significant differences in grieving reactions and substance abuse; parents who lost children due to head trauma reported more substance abuse whereas parents of children with schizophrenia reported more ongoing grieving (Atkinson, 1994). Based on these results, the experience of parents who lose a child to a mental illness such as schizophrenia is characterized by chronic grief. With this in mind, research should focus on grief experiences of family members of those with a wide array of severe mental illnesses. The experience of parents differs based on the attributed cause of their children's mental illness (Atkinson, 1994). It seems that schizophrenia may be deemed as organic and more genetically based than a head injury that may be more easily attributed to an outside force. Parents experiences differ based seemingly on responsibility attribution of their child's mental illness and should be further investigated, possibly by conducting future research that examines parental responsibility attribution of different types of biologically based disorders.

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Research investigating parental experiences of taking care of children with mental illness continued with goals broadened to examine the experiences related to other serious disorders, such as bipolar disorder. Eakes (1995) examined the experience of chronic sorrow in parents of children with severe mental illness. Ten parents, four couples and two mothers, of children with schizophrenia or bipolar disorder, were interviewed. Researchers used the *Burke/NCRCS Chronic Sorrow questionnaire (Caregiver Version)*. Results indicated that 80% of parents experienced chronic sorrow, most often due to the limitless responsibilities described by the parental caregivers. Parents reported that helpful interventions from healthcare providers would include being provided psychoeducation about their child's mental illness and by being included in the treatment process (Eakes, 1995). Because parents experience chronic sorrow, their ability for effective caretaking may be lessened, especially if chronic sorrow increases the chance of burnout because their grief goes unnoticed and untreated.

Despite the lack of many studies utilizing strictly interview methodology, Tuck et al. (1997) focused on the experience of caretakers of adult children by utilizing phenomenological methodology. A member of the research team interviewed nine participants, sampled from mental health professionals or a support organization. Over two-thirds of participants were female, White, and all were middle class. All of the adult children with severe mental illness were male and had been diagnosed with either schizophrenia or schizoaffective disorder within the last 10 years. Themes that emerged among the participants' responses highlighted struggling to normalize the events, help-seeking behaviors and experiences, witnessing the changes in their child, experiencing vacillation in hope for the future, caring as a full-time job, attempting to make meaning,

and taking care of oneself, along with framing events as pre-diagnosis and post-diagnosis experience with an emphasis on the impact of the diagnosis itself (Tuck et al., 1997). From this, a strictly qualitative experience was understood, but given the small and conveniently-sampled number of participants, more interviews are needed that span socioeconomic status, type of severe mental illness in affected family member, age and developmental group, and sex of affected family member.

Previously, studies focused on parents of children with one diagnosis, aimed toward specifically understanding experiences of parents of children with schizophrenia. Research was needed to understand the specific types of loss parents experienced when their children had severe mental illnesses other than schizophrenia. Dore and Romans (2001) examined the effect of the role of caregiving on 41 participants using in-depth interviews. Caregivers consisted of parents and partners living with an adult loved one diagnosed with bipolar disorder. Interviews revealed that participants experienced negative vocational, financial, legal, social, and interpersonal implications particularly when their loved one was experiencing active symptoms of their disorder, although participants' own mental health appeared unaffected. Of particular worry to both male and female participants was the activation of violence in their manic family member, with suicidal ideas and acts next. Distressing manic behaviors were described as impulsive shopping and spending, bizarre behaviors, hyperactivity, and significantly increased speech. Despite the aforementioned findings, caregivers' reports indicated commitment to their loved ones and tolerance of symptomatic, problematic behaviors. Findings indicate that practitioners should include caregivers, even romantic partners, in therapeutic interventions. This research highlights the types of losses experienced by

parents and, importantly, when they are most likely to experience these losses (Dore & Romans, 2001). This might mean that to gain the most accurate picture of parents' experience, research should focus on parents' perceived most critical incident involving their child's mental illness.

Much of the extant research has utilized a one-time interview methodology. Recognizing that longitudinal research was lacking but was needed to better understand how symptoms, reactions, and the grieving process change over time, Mohr and Reagan-Kubinski (2001) focused on the patterns in grief of parents whose adult children were diagnosed with mental illness. Specifically, the researchers wanted to gain insight into how parents experience transition related to their child's onset, progression, and reality of living with a psychological disorder. Four hour-and-a-half focus groups were conducted over a four-week period about these parents' experiences with the goal of better understanding the needs so that future interventions and supports could be developed and implemented for working with this population. Four dyads of married parents of children diagnosed with schizophrenia or a major affective disorder, warranting hospitalization at some point, were recruited by announcements made by group leaders of five community support groups for relatives of someone with psychopathology. Their children ranged in age from 17 to 31 years. The process group focused on participants sharing their feelings with each other rather than elaborating on their child's diagnosis. A follow-up group was conducted after three months. The researchers point out that the small sample size may not be representative of all parents experiencing loss and grief as a consequence of their child's mental illness diagnosis.

Seven themes were identified: early nightmares, action, overwhelmed, fear, anguish, guilt, and sequale (Mohr & Reagan-Kubinski, 2001). Descriptions from parents identified in the last theme seemed closely related to posttraumatic stress, with parents reporting recurrent nightmares of leaving their ill child on a locked ward, reliving and replaying leaving their children on wards and hearing the locked doors slamming, and reliving the memories of the day their child was committed to an inpatient ward. One main implication is challenging the notion of viewing the family as needing fixing or blaming family dynamics for an identified patient's symptomology. Rather, families should be conceptualized using a grief model, not pathologized or viewed as dysfunctional. It is notable that parents do not necessarily experience one stage of grief at a time, rather they may vacillate between stages or experience multiple stages concurrently. In order for parents to better support their children, their grief and loss must be acknowledged and they too must be supported. These findings highlight the importance of parents' influence on their children's wellbeing and development. Clinicians were urged to intervene with parents and focus on the family system, rather than strictly the identified patient (Mohr & Reagan-Kubinski, 2001). Because parents may experience grief cyclically or experience more than one stage at a time, it is important that future research highlight and normalize this fact to participants as to gain a more accurate picture of functioning.

The Parental Experience of Children with SPMI who Live at Home, Transition, or Live away from Home

Although symptoms of loss and grief received limited examination in the extant research, understanding the experiences of parents transitioning their children away from

home due to a child's mental illness is even less understood. Unfortunately, because of severe symptomology, this is the reality for some parents, and their explanations and elaboration of their experiences are vital to understanding loss and grief in parents of children with the most severe psychopathology. Cook (1988) researched the experience of parents who served as caretakers for their adult children with severe mental illness during the transition of their child from home to a community treatment residence. Forty-nine parents of young adults with mental illness were interviewed using interviews, questionnaires, and observation when researchers conducted home visits with patients and their families. These interviews were conducted during the child's transition from home to a psychiatric rehabilitation program.

Even with variables such as parents' education, ethnicity, age illness duration, and offspring's sex being controlled, mothers reported significantly higher levels of depression, anxiety, fear, and emotional drain than fathers (Cook, 1988). Parents who were pushed down flights of stairs, witnessed their children smashing windows, were punched by their children, or witnessed or were the target of violence from their children reported experiencing fear. Given the threat of or experience of violence, toward themselves or others, parents understandably may be experiencing symptoms of acute stress disorder or posttraumatic stress disorder. Further research utilizing means to quantitatively assess these symptoms is necessary. The author asserts that these findings point to interventions for mental health providers and the need to avoid pitfalls commonly found in therapy, such as mother blaming and scapegoating (Cook, 1988). It seems as if the more symptoms a child with mental illness is experiencing, and therefore receiving more needed accommodations, the more grief and internalized symptoms a

parent will experience. It is notable that more severe psychopathology in children may create more severe symptoms in parents, especially as parents are in the position to make decisions about treatment, living arrangements, medications, and other related variables (Cook, 1988). In order to provide the best treatment for children with mental illness, parents' negative emotional experiences must be understood and addressed as to positively interrupt a possible negative feedback loop between child symptomology and parental grief reactions.

Although the negative effects of having a family member with a severe mental illness have been previously shown, Ryan (1993) was the first to qualitatively explore the experiences of caregivers. Ryan (1993) conducted interviews with mothers who served as primary caregivers for their adult children who were living with schizophrenia. Her aim was to utilize an ethnographic method in order to understand the mothers' worldviews from their perspectives. Specifically, the researcher aimed to capture how the mothers defined and managed their situations on a daily basis. Five mothers were conveniently sampled from a support group. They were White women ranging in age from 50 to 62 years. Each had a child diagnosed with schizophrenia who was 22 to 38 years old, and the range of time the adult children had been living with schizophrenia was from six to 20 years. The researcher interviewed and audio-recorded each of the mothers, relying on descriptive, structural, and contrast questions. Three of the mothers were interviewed a second time to help validate findings of the first interview and help guarantee that researcher biases had not influenced research outcomes.

After the interviews had been transcribed and themed, researchers found a common thread among the mothers' experience: *a lifetime of mothering*, meaning that the

mothers felt there was no point of being finished with being an active caregiver for their

adult children (Ryan, 1993). This theme was comprised of two main experiences:

disruption and loss. Disruption encompassed disruption of the caregivers' lives as well as

disruption in the relationship between the caregivers and their adult child with

schizophrenia. Mothers, therefore, were faced with the task of managing both types of

disruption. They reported specifically managing symptoms of their children's mental

illness by normalizing, accommodating, and setting limits with their children. The

disruption in their life was defined as constant, central, and uncertain and was highlighted

by instances of the mothers' focus being on trying to find more information on

schizophrenia as a way to advocate for their children and educate themselves, and of

reporting feelings of uncertainty about the future and the unpredictable course of the toll

their children's illness would take. The mothers described loss as capturing the loss of

their freedom as well as the loss of the children's potential for the future. Mothers

described managing this loss, but there were no central themes among the mothers in how

they managed.

The findings of Ryan's (1993) interviews indicate that not only do mothers feel

loss when their child is diagnosed with schizophrenia, but they continue to feel loss

throughout the years of caregiving for their adult children. What is unknown is if mothers

who are caregiving for their adolescent or pre-adolescent children also feel loss in a

similar way, or how they manage this feeling of loss. It is also unknown, from an

ethnographic view, how parents who are caregivers for their children under the age of 18

years respond when their child is diagnosed with a severe mental illness other than

schizophrenia. Research is needed to understand parents' experiences and it may be

fruitful to explore this while their diagnosed children are younger, and therefore the experience of finding out and beginning to provide care in a different way is more salient.

Initially, the examination of the stages of grief in relation to the diagnosis and care of a child with mental illness was needed. Howard (1994) investigated the experience of mothers taking care of adult children with schizophrenia, framing their experiences within a lifespan perspective. Using both grounded theory and naturalistic inquiry, 19 interviews averaging four hours each were conducted with 10 participants. Interviews were coded and themed by the researcher. From the transcripts, researchers developed a model of stages of learning in the experience of being a mother caretaker of an adult child with schizophrenia. Four stages were identified: perceiving a problem, searching for solutions, enduring the situation, and surviving the experience. The researcher urges that this model be used in developing and utilizing intervention and education models. This research was groundbreaking at the time and highlighted maternal experiences of caring for children with a severe mental illness. This research highlighted the stages of finding out about illness in a child and the effects of caregiving. Also, it was highlighted that more than the diagnosed person living with the illness, the caretakers are highly affected. One major conclusion of this study was the possibility of maternal caregivers experiencing post-traumatic stress disorder based on their words used to describe their caregiving experience. Parents described their caregiving experience with words including "'battling,' 'shock,' 'devastation,' 'terror,' 'nightmare,' and 'sick with worry'…" (Howard, 1994, p. 113). Based on this finding, research that examines post-traumatic stress disorder symptomology in caregivers should be conducted, and research should identify how these symptoms interact with symptoms of grief and loss.

Although studies focused on the lived experience of caretakers of children with mental illness, few had examined loss and grief during transitional periods. Crisanti (2000) aimed to understand mothers' experiences of adult children with schizophrenia. More specifically, the researcher interviewed mothers about the involuntary hospitalization of their children. Three mothers' perceptions and accounts of the experiences were examined using phenomenology after open-ended interviews were conducted. From these interviews, common themes and elements were highlighted. Overall, mothers seemed to report negative experiences and, as a result, reported feeling anxious, judged in a negative light, and baffled. Mothers reported negative interactions with the mental health system and its providers and felt they lacked support (Crisanti, 2000). From this, one can surmise that parental loss, grief, and negative internalized symptoms are affected not only by a child's mental diagnosis, but also by transitions to more intensive treatment and the help received and interactions at treatment facilities. This speaks to the importance of assessing experiences of help seeking for children in relation to parents' experiences.

Although research in the past focused on the experience of caretakers of adult children living with a severe mental illness who either lived at home or were transitioning away from home for acute or long-term care, no research had been conducted to explore parents' experiences when their children were living in a long-term care setting. Pejlert (2001) aimed to explore how parents made meaning of their role and relationship with their children with schizophrenia who were living away from home in a care facility. Eight parents – three couples, one father, and one mother – of five clients who had transitioned from a hospital ward to a care facility setting three years prior were

interviewed. Originally, 10 clients had been transitioned but only six, two men and four women, were still in care at the facility. The patients were, on average, about 42 years old and had been diagnosed with schizophrenia at about the age of 19 years, on average. Parents' amount of contact ranged from visiting sometimes, daily, at the end of the week, or visiting by telephone. Although clients and nurses had been interviewed before the move, one year after the move, and two years after the move, the present research focused on interviewing the parents three years after the move (Pejlert, 2001).

Parents were interviewed and recorded by the researcher and asked to elaborate about their relationship with their children in the past and present, and how they felt about the future (Pejlert, 2001). After the audio-recorded interviews were transcribed, a phenomenological hermeneutic approach was used to understand the meaning of the experiences shared by the parents. Five major themes were found: living with chronic sorrow, living with guilt, relationships with care practitioners, accepting hardships, and wanting better for their adult child (Pejlert, 2001). Of particular importance, parents described living with sorrow for the child they felt the had lost, despite the child being alive, including the potential of the life the child could have led if not for being diagnosed and living with schizophrenia. One could interpret that parents may also feel a loss of their role as a caregiver since their children no longer live at home and are physically managed and cared for by others. However, this sort of loss has not been explicitly studied. Future interviews should assess how parents identify their role shift, if at all, and should focus on parents who have non-adult children who are living away from home due to a severe mental illness.

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Although experiences of caretaking for children with mental illness had been examined, there had not yet been a constructed narrative of how living with and caring for a child with mental illness for years affected parents. Ozgul (2004) aimed to construct a narrative of the grief and loss experienced by parents of adult children with schizophrenia. A focus group of 22 participants was formed by parents (16 mothers; 6 fathers) who responded to flyers distributed at community mental health service providers. These parents had been living with their now adult children for years, although the researcher did not specify the exact amount of time. During the focus group, participants described their experiences pertaining to their child's mental illness from onset of symptoms to the present time. They were also asked to reflect on and describe types of support parents would need at different stages in adjusting to their child's mental illness.

It was found that diagnosis initially brought a sense of relief, but upon the realization of the enormity and severity of the reality of the diagnosis, these hopeful feelings turned into sadness and grief (Ozgul, 2004). Participants described struggling to believe the reality of the diagnosis, a feeling that coincided with the onset of grief, and feeling cheated. Parents began to feel helpless and hopeless as the reality of the diagnosis solidified, coupled with anger and frustration. These feelings were described as being exacerbated by feelings of isolation both by society and by their adult children. Intrusive thoughts and harsh reminders of the diagnosis were described by parents, especially imminent during times of celebration or milestones during others' lives. Parents described that they were better able to adjust when they felt supported; better understood the illness's symptoms, progression, and treatment; and when they encountered empathy.

Even with these supports, parents seemed to experience complicated grief in that it had no distinct beginning or ending; rather the relationship with grief ebbed and waned with the ongoing relationship and growing-dependency of their adult child (Ozgul, 2004). This research speaks to the importance of acknowledging the cyclical nature of grief and the impact of severity and duration of children's mental illness symptoms.

Grief among Fathers

Much of the research of parental loss and grief was initially conducted with mothers. When fathers were included as participants, they were mostly included in a couple-dyad and sex was not looked at as a distinctive factor. Davis and Schultz (1998) studied the impact of having a child with schizophrenia on the symptoms of loss and grief in parents. The researchers' goal was to identify and confirm the presence of grief in these parents, both mothers and fathers, and to examine if grief reactions were affected by the number of contact hours spent between parents and children. Sixteen mother-father dyads with adult children living with schizophrenia completed a self-report questionnaire, *The Impact of Event Scale – Revised* (*IES-R*; Weiss & Marmar, 1997). On average, parents were 62 years old, and their child had been diagnosed with schizophrenia for over 10 years (Davis & Schultz, 1998). Results indicated that parents were experiencing grief related to their child's mental illness. Both mothers and fathers reported distress, unwanted thoughts, and avoidance behaviors. Mothers' and fathers' grief was not impacted by number of parental contact hours with their child, with the exception of intrusive thoughts acting as an intervening variable. Because of this, the importance of including fathers in participant samples was highlighted. Also, considering the number of hours a parent spends with a child, instead of strictly identifying participants as parents,

raises interesting implications for possible attachment-style relationships that are affected by a child's persistent mental illness (Davis & Schultz, 1998). Although the researchers considered intrusive thoughts, being upset by reminders of the loss – *reminders* being largely undefined, and utilizing avoidance behaviors to characterize grief, one could conceptualize these symptoms as those of a traumatic reaction. Given that the *IES-R* (Weiss & Marmar, 1997) was utilized as a measure for grief, one could argue that it would better be used as a measure for symptoms of trauma, and therefore that the construct of grief could be split to better differentiate between traumatic and grief reactions.

As research about parental experiences of having and caretaking for a child who has a severe mental illness progressed, little research was focused on the experience of fathers. Wiens and Daniluk (2009) explicitly focused on understanding the paternal experience of the relationship with their child prior to diagnosis, at diagnosis, and after diagnosis. Specifically, the researchers aimed to gain an understanding of fathers' experiences when their young adult child had been diagnosed within a decade. Given that much of the past research has not specified a timeframe of diagnosis or onset as participant inclusion criteria, the researchers asserted that parental reports might have been biased or forgotten due to the amount of time that had passed since their children's initial diagnosis. The researchers recruited six White fathers, who ranged in ages from 40 through 70 years, from local clinics and support groups in a large city on the West Coast. Each father had a young adult child, ages 18 to 35 years, who had been diagnosed with schizophrenia. The children had been diagnosed for approximately four to eight years, and only one child was currently living at home due to severe symptomatology.

Fathers were interviewed and audio-recorded using a somewhat structured interview (Wiens & Daniluk, 2009). Interviews ranged from an hour-and-a-half to two-and-a-half hours. The researches used a phenomenological approach to explore the fathers' experiences and uncover their internal meaning they had created around their experience of having a child diagnosed with schizophrenia. Data were analyzed as dictated by the qualitative procedure, and six themes were found amongst participant responses, including reflection on roles as a parent, a sense of devastation, a sense of loss, a sense of irritation with the health system, a sense of admiration for the diagnosed child, and a sense of personal growth. The theme of loss was created by the identification of five particular losses, including loss of their pre-diagnosis child, loss of their child's future, loss of their child as a part of society, personal losses, and loss of their own anticipated future (Wiens & Daniluk, 2009). Given these findings, it seems that fathers had a great deal of elaboration and catharsis when given the chance to speak about their experiences. Very few fathers, proportionally, are included in research, especially qualitative interviews. Future directions should make an effort to include an equal number of fathers as well as to diversify the cultural makeup of participants. Fathers who have children under the age of 18 years should be sought to see if their experiences of loss and sadness are comparable to the fathers who have been interviewed about their experience with adult children who have mental illness.

Research supports that grief is a real, lived experience for parents who have children with severe and persistent mental illness. Not only is this grief nonlinear but is cyclical, but also, for most, it is chronic with no endpoint of the loss in sight. Although this experience has been captured in parents of adult children with severe mental illness,

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it is unclear as to if the experiences are paralleled in parents of non-adult children. By tapping into these parents' experiences, a clearer understanding of the beginning stages of grief can be gained. Although previous research has utilized parents with adult children, it is unknown what the subjective experiences of these parents were since their perceptions may change over time and they were not accessed closer to the onset of illness, even before an official diagnosis was given to their children. By instead utilizing parents of non-adult children with severe mental illness and exploring their experiences, the understanding of whether grief experiences are similar in strength and trajectory will further the overall understanding of loss and grief in parents, and can eventually contribute to creating and implementing more beneficial interventions for not only the patient, but for the family system as a whole.

Risk and Protective Factors

Although loss and grief in parents has been researched, little had been conducted examining the ways in which parents cope with their child's mental illness. Osborne and Coyle (2002) aimed to assess if parents' responses to adult children with schizophrenia could be conceptualized in terms of loss and grief. The researchers explored this by conducting a case study analysis on four narratives of parents. Using Interpretative Phenomenological Analysis (IPA), researchers sought to identify and understand coping mechanisms parents use to deal with feelings incited by their child's mental illness. The overarching goal of this research was to learn how to better therapeutically support and work with parents of adult children with schizophrenia. Although loss was a prominent description amongst parents, the degree of loss seemed to differ among participants. Seventy-five percent of the sample recognized and reported a sense of loss, while the

fourth participant objected to feeling loss as well as to the validity of her child's

diagnosis of schizophrenia. Researchers attempted to understand if feelings of grief were

related to the loss of the pre-morbid version of their child; one parent hinted at feeling

this loss but negated it by focusing on the sustained physical presence of his child

(Osborne & Coyle, 2002). This highlights the importance of gauging the duration of a

child's mental illness when interviewing parents. It is possible that the parent who

resisted interpreting her feelings as loss had just learned of her child's diagnosis.

Duration of the child's mental illness should absolutely be considered and assessed for in

future research.

Although the presence of grief has been identified and empirically supported in

parents who have a child with mental illness, other factors that were affected by a child's

diagnosis had yet to be examined. Godress et al. (2005) extended the previous research

by measuring symptoms of grief, health, and parent-child attachment relationships in

parents whose children had a severe mental illness. By measuring grief, the researchers

aimed to understand the relationship between grief symptomatology and health status, as

well as the relationship between parental grief and parent-child attachment relationships.

It was hypothesized that those with secure parent-child relationship attachments would

have lower levels of grief whereas those with an anxious/ambivalent or avoidant parent-

child relationship attachment would experience higher levels of grief (Godress et al.,

2005).

Participants, 62 mothers and nine fathers, were recruited from support agencies

throughout Australia (Godress et al., 2005). On average, they were 57 years old and all

had a child who was diagnosed with a severe and persistent mental illness. Over 80% of

the children had been diagnosed with schizophrenia or schizoaffective disorder, while the remaining children, with the exception of two, were diagnosed with bipolar disorder. The children were, on average, aged 28 years old, and lived either with their parents, with a friend, in group homes, on their own, or were in the hospital. Children had been diagnosed an average of seven years prior to the study, ranging from three months to 28 years ago. Parents were mailed the self-report questionnaires that consisted of two grief measures, a health measure, an attachment measure that was adapted from a previously well-validated measure, and an affective relationship measure that was created for the present study. Results indicated that grief was present in these parents, although inversely correlated with time measured in years since their child's initial diagnosis. The researchers also found support for their hypothesis that lower levels of grief were significantly related to a secure parent-child attachment whereas higher levels of grief were significantly related to an anxious/ambivalent parent-child attachment relationship (Godress et al., 2005).

Interestingly, the two measures used by Godress et al. (2005) to measure grief were the *MIV-TIG* (Miller et al., 1990) and the *Impact of Event Scale* (*IES*; Weiss & Marmar, 1997). Grief was defined as a reaction to loss through cognitive, emotional, and behavioral means. Part of this operational definition included avoidance behaviors and intrusive thoughts (Godress et al., 2005). Conceptually, these could also be deemed as symptoms of a traumatic reaction. Traumatic reactions are characterized by a person fearing physically or mentally re-experiencing an event, therefore being hypervigilant of surroundings and even avoiding possible triggers, reminders, or possible experiences related to the event. Traumatic reactions are possible, even when a person does not meet

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diagnostic criteria for posttraumatic stress disorder (PTSD), and could result from prolonged exposure to stressors, from one traumatic medical emergency or psychological crisis, or from a combination of these causes. Even without necessarily witnessing violence to oneself or their child, parents report hypervigilance of watching for symptoms of their children's illness to return. Therefore, research focusing on using the existing *IES-R* as well as another trauma symptomatology screener to identify and validate the presence of traumatic reactions in parents with children who have been diagnosed with a severe mental illness would be significant.

Along with loss, grief, and internalized symptoms, little attention had been paid to resiliency factors and wellbeing predictors for parents. Depressive and burden symptoms may outweigh existing wellbeing factors, and a new goal was to identify when specific factors would be more prominent. Chen and Lukens (2011) reviewed archival data to study the impact of caregiving on parents and siblings of a loved on with mental illness. Their goal was to examine both risk and protective factors for wellbeing, depressive symptoms, and subjective burden. Results of multiple regressions revealed that well-being was increased for caretakers who were siblings compared to those who were parents. Decreased well-being, increased depressive symptoms, and increased subjective burden were found among those exposed to risk factors such as grief and increased family stress. Caretakers being proud of their relative exacerbated depressive symptoms, but this pride protected against burden. This finding challenges the assumption that the caregiving experience is completely negative. Despite this counterbalance, it is noted that feeling proud of the loved one was a separate experience from that of the caregiver's assessment of personal well-being. All caregivers who had social support were protected

against depressive symptoms. The authors discussed practical interventions for promoting resilience and addressing caregiver challenges (Chen & Lukens, 2011). Along with identifying depressive and burden symptoms, identifying factors promoting wellbeing is important for treating caregivers in a solution-focused manner. In order to fully understand the full extent of parents' experiences, a holistic understanding of both strengths and weaknesses in the process of taking care of a child with mental illness is imperative. This may speak to the importance of highlighting parent strengths during research interviews as to increase hope and self-efficacy.

Burden

Although the presence of grief had been explored in past studies, research had not yet expanded to examine what other characteristics of both family members and patients impacted the degree of grief experienced by family members. Solomon and Draine (1996) extended the study of familial experience of grief by researching how a family member's emotional response to a relative's mental illness is impacted by their own personal characteristics, their perceived social support, their experience of subjective and objective burden, and the severity of their loved ones' mental illness. The authors made a clear operational distinction between grief and burden. Grief, as defined by the researchers, is thought to be an emotional response to loss, that when compounded by long term illness and, therefore, long term reaction can be thought of as chronic sorrow: an exacerbated and more permanent form of depression. Burden, both subjective and objective, was defined as the extent to which a family member is responsible for their loved one with a severe mental illness. Whereas objective burden captures observable stressors the family experiences, subjective burden is the personal sense of obligation and

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pressure to meet the strains of caring for their mentally ill loved one. The researchers hypothesized that grief would be greater when objective and subjective burden were increased, as well as when the loved one suffered from a more severe mental illness (Solomon & Draine, 1996).

Participants from a large East coast city were recruited from a wide array of departments, programs, and advertisements (Solomon & Draine, 1996). Eligibility consisted of being the family member of someone diagnosed with a severe mental illness, being in at least weekly contact with the person with the illness, living near the city in which the research was being conducted, the family member with the mental illness had been diagnosed with schizophrenia or major affective disorder at least six months before recruitment, and both the participant and the ill family member were over 18 years old. Of the 244 family members who met criteria, 225 gave consent and participated in the study. Close to 90% of the sample were female, White, and were, on average, about 56 years old. Over 75% of the sample was parents of an adult child with a severe mental illness. The majority of the relatives with mental illness had a diagnosis of schizophrenia and they were, on average, about 36 years old. Participants were interviewed using the *MIV-TIG* (Miller et al., 1990) and filled out self-report questionnaires focused on demographic information, functioning, burden, and social support (Solomon & Draine, 1996).

Results of a hierarchical block multiple regression revealed that family characteristics, severity of the mental illness, social support, and both types of burden were able to explain grief among family members (Solomon & Draine, 1996). When controlling for social support and the severity of the relative's mental illness, burden

explained the largest proportion in the analysis (Solomon & Draine, 1996). This is

conceptually important as burden and grief are different constructs, but might not be

mutually exclusive; in times of increased burden, there may be increased grief, especially

since grief is experienced in a cyclical manner and burden can increase in any given

moment based on mental health crises of a loved one with a mental illness. Given this, it

is important to further explore the individual experiences of caregivers and how they

conceptualize both their grief and burden experiences and how they interact to impact the

lived experience of coping with a loved one's diagnosis of a severe mental illness.

Despite the examination of loss and grief in research, there was a paucity of

research focused on burden and the types of burden. Specifically, it was important to

investigate the relationship between responsibility attribution for symptomatic behaviors

and subjective and objective burden in caregivers. Provencher and Mueser (1997)

examined the relationships between caregiver burden and perceived severity of patient

symptoms and attribution of responsibility for behaviors associated with positive and

negative symptoms. Burden was divided into two types: Objective burden was defined as

negative results such as health problems, interpersonal and family difficulties, and

financial troubles, and subjective burden was defined as emotional distress of caregivers

related to symptomatic behaviors of patients. Researchers hypothesized that objective and

subjective burden would be related to the severity of positive and negative symptomatic

behaviors, and caregivers would experience less objective and subjective burden in

relation to attributing less responsibility to patients for their positive and negative

symptomatic behaviors. Seventy Canadian caregivers of adults with schizophrenia or

schizoaffective disorder were conveniently sampled from therapists and self-help groups.

They completed self-report interview measures consisting of the *Behavioral Disturbance Scale (BDS), Subjective Burden Scale (SBS), Objective Burden Questionnaire (OBQ)* – all modified versions of scales included in the *Social Behavioral Assessment Schedule (SBAS)* – and the *Responsibility Attribution Scale (RAS)*. Caregivers were, on average, about 60 years old and mainly female. The majority of the sample was White and the parent of the mentally ill patient. The average age of patients was about 35 years old. Most patients were male, never married, unemployed, diagnosed with schizophrenia, and had been hospitalized about six times. Researchers conducted interviews in the private homes of caretakers or caretakers' friends, or at a library (Provencher & Mueser, 1997).

Results indicated that subjective and objective burden were significantly correlated (Provencher & Mueser, 1997). Severity of positive and negative symptom behaviors were related to subjective burden of caregivers, but only the severity of negative symptoms behaviors was related to objective burden. This finding partially supports the researchers' first hypothesis. The types of burden were affected by different patient variables; higher levels of objective burden were reported by caregivers who attributed less responsibility to patients for their negative symptoms, and this finding stands in opposition to the researchers' second hypothesis. Objective burden, however, was not impacted by caregivers' views toward patients' responsibility for positive symptoms behaviors. In other words, caregivers experienced more tangible types of loss when the patient exhibited more negative symptoms, and this increased objective burden was not based on if caregivers view of if the patient was responsible or not for their positive symptoms. The researchers note several limitations to their study. Firstly, many caregivers belonged to a nationally known support group (National Alliance for the

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Mentally Ill; NAMI), which may indicate that these well-educated and financially comfortable members do not best represent the population of caregivers. Next, actual symptom severity of patients was not obtained, only caregivers' perceptions of symptom severity. Lastly, findings were not statistically robust (Provencher & Mueser, 1997). These limitations leave options for future research to replicate this study in order to further explore the relationship between responsibility attribution and objective and subjective burden in caregivers.

Along with responsibility attribution, one must consider how burden is affected by the amount of time spent by parents taking care of children with mental illness who are living at home. Ricard, Bonin, and Ezer (1999) investigated the subjective burden experienced by caregivers of mentally ill family members living at home. Patient files were randomly selected from eight psychiatric hospitals in Montreal. Files were then examined to ensure that patients were still receiving treatment from an outpatient clinic, seen at least once in the past three months, and had not been diagnosed with substance abuse disorders or cognitive deficiencies. Patients recruited were individuals living in the home with a familial caregiver. Caregivers – identified by patients as those who provided them the most care – were eligible for inclusion if they were between the ages of 18 and 75 years, had lived in the same home as the patient for at least half a year, had not received inpatient or outpatient psychiatric treatment in the last three years, and were fluent in French. The response rate for participants was 36.3%. On average, caregivers were 51 years old and almost half were men and half were women. About three-quarters were married or in a long-term, committed relationship. One-fourth of caregivers made between $30,000 and $50,000. Patients were comprised of women more-so than men, and

about half had completed high school although only one-fifth had jobs in the community. The patients were almost evenly divided by types of diagnoses: about one-third was diagnosed with schizophrenia or psychosis, about one-third was diagnosed with an affective disorder, and about one-third was diagnosed with anxiety or personality disorders (Ricard et al., 1999).

Interviews consisted of the *Social Behavior Assessment Scale (SBAS)* – a standardized semi-structured interview used for assessing subjective burden in caregivers – and 34 closed-ended questions (Ricard et al., 1999). Sections assessing caregivers' burden related to patients' behavior disturbances, patients' interpersonal functioning disruptions, and negative consequences of patients' behaviors on others were given. Caregiver distress was affected by subjective burden associated with behavior disturbances of the patient, along with negative impact on the household by the patient. About one-tenth of the caregiver sample reported experiencing no subjective burden in experiencing difficulties with the patient. Combined patient and caregiver variables accounted for almost 75% of the variance in total subjective burden. Much of the variance was explained by the patient's current mental state. Variables related to objective burden – such as the patient's current social dysfunction and pathological behaviors – also explained some of this variance. Overall, patients' symptomatic behaviors resulted in greater burden than their social troubles. Results, however, lack generalizability due to the low response rate of participants. Also, the measurement of subjective burden is questionable due to the use of the SBAS as it measures both subjective and objective burden along with patient problems. It is also impossible to precisely identify the levels of burden from different sources. The authors recommended

that future studies focus on the various dimensions of caregiver burden, possibly to be explored in a longitudinal study (Ricard et al., 1999). Because it seems living with a family member with mental illness increased caretaker burden, longitudinal studies would better capture the experience of and changes in degree of burden symptoms in caregivers. One may also examine how burden impacts feelings of grief and is, in itself, a type of loss.

Subjective burden was also researched in parents of adult children with severe psychopathology. Jungbauer, Wittmund, Dietrich, and Angermeyer (2003) conducted a follow-up study in Leipzig, Germany to measure the subjective burden in parents of adult children with schizophrenia. Two-thirds of the parents who were initially contacted were interviewed about subjective burden using a narrative technique, resulting in 51 participants. Caregivers were, on average, 60 years old and consisted mainly of mothers of patients with schizophrenia. Patients were, on average, 33 years old and close to half still lived with their parents. Most patients had participated in psychiatric treatment for about 11 years. Patients were found to be functioning with moderately severe impairment as evidenced by a psychiatrist diagnosing patients with an average Global Assessment of Functioning (GAF) score of 52. Researchers, who utilized a narrative interviewing technique, completed data collection during home visits that lasted about 30 minutes. Data was collected at six-month intervals for 18 months. Questions focused on any changes in participants' situation regarding their child's mental illness, any experienced burdens, and how time had been occupied. During the study, three participants dropped out, leaving 47 interview sets. Of these, 40 interview sets included parents who

participated in all three interviews and seven sets included parents who participated in two interviews (Jungbauer et al., 2003).

After reviewing the 47 interviews, six developmental types of subjective burden were identified: constantly high, increased, reduced, shifting, preeminence of others, and constantly low (Jungbauer et al., 2003). During the study, 40% of participants indicated a constantly high level of burden. Change or constancy in level of burden seemed closely linked and consistent with adult children's course of mental illness. Results indicated that parents of children with severe and persistent symptomology were especially strained and were particularly in need of support. Overall, results indicated that parents of patients with schizophrenia may have differing experiences in their burden development. Researchers noted that most parents interviewed were mothers and this could indicate a selection effect, especially given the possibility that mothers of children with schizophrenia may experience more burden than their male counterparts. Secondly, only parents whose child approved their parents' participation in the study were contacted and included in the study's sample. This selection may have eliminated interviews with parents whose children were particularly ill – those experiencing severe paranoia or other extreme symptoms – or parents who eliminated themselves possibly due to already being emotionally drained (Jungbauer et al., 2003). Future research should replicate this study but broaden the sample of participants. Results that are more generalizable will lead to more applicable interventions that give attention to excessive demands placed on parental caretakers of children with chronic mental illness. In-depth interviews are imperative for better understanding what factors contribute to this moderate to high level of burden experienced by caregivers living with children diagnosed with severe mental illness.

Burden is experienced in parents in both tangible, objective ways as well as in perceived, subjective ways. The presence of objective burden has been identified in parents, especially when they have a child who has a severe mental illness and exhibits increasingly more negative symptoms. Levels of objective burden are not dependent on whether the caretaker is able to identify an external cause or attribute responsibility of positive symptoms within their child. Overall, burden seems to be increased as proximity to the child increases, such as children with a severe mental illness living at home with their parental caretaker, and seems to be highly consistent with the course of the children's mental illness. Therefore, the current study aims to understand if objective and subjective burden is felt in similar ways for parents of non-adult children who have severe mental illness as it is in the parents of the aforementioned studies.

The Experience of Parents with Adolescent and Pre-Adolescent Children with SPMI

Despite the vast research conducted on parents of adult children with psychopathology, little research had been conducted on parents of non-adult children with severe and persistent mental illness. Richardson, Cobham, McDermott, and Murray (2013) examined the experience of parents of child or teen patients with psychopathology. They aimed to investigate if these parents' experiences were similar to or different than those of parent caretakers of adult children with mental illness. Fourteen parents (11 mothers; 3 fathers) and one custodial grandfather were recruited by clinic staff and flyers at a Child and Adolescent Mental Health Service (CAMHS) where their children were receiving assessment, treatment, and follow-up services. Parents ranged in age from 41 to 59 years, but on average were about 49 years old. Their children ranged in age from eight to 18 years, but on average were about 14 years old. Over half of the

sample reported previous or current mental health problems. Youth patients had been

engaged in CAMHS for 3.5 years, on average. Youth diagnoses included anxiety

disorders (e.g., obsessive compulsive disorder, separation anxiety disorder, generalized

anxiety disorder, anxiety disorder unspecified), anorexia nervosa, language disorders,

oppositional defiant disorder, and self-injurious behaviors. Participants completed a

demographic questionnaire and an hour-long interview assessing parents' initial reaction

and current response to their youth's diagnosis, coping strategies and social support, their

perceived experienced stigma, their opinion on care received, and thoughts about what

types of support would be helpful for parents in their situation (Richardson et al., 2013).

Using inductive thematic analysis, six themes were identified (Richardson et al.,

2013). The first theme was of realizing their child was ill. This event was characterized

by feelings of anxiety, reports from others about their child's functioning, and worsening

of their child's symptoms. The second theme was profound loss characterized by the

image of their child's true nature being destroyed, destruction of parental expectations for

their child, feeling uncertain about their child's future, feeling a loss of control and

confidence as a parent, and their child's mental illness impacting family decisions. The

third theme was that of complex grief characterized by experiencing an intense longing

for the relationship they had with their less-symptomatic child, and attempting to utilize a

plethora of coping strategies. The fourth theme was that of feeling isolated and

unsupported, characterized by feeling unsupported by their extended families, their

child's school, practitioners involved in their child's treatment, and therefore feeling the

need to hide their child's illness from others. The fifth theme was that of juggling

responsibilities with those of supporting their child's treatment characterized by time

conflicts with work and taking their child to treatment, attending meetings at school, and meeting all financial obligations. The last theme was that of considering the kind of support needed for parents with children with psychopathology characterized by a need for empathy from professionals, psychoeducation, and learning to reflect on expectations about the future. Parents experienced a significant amount of loss and grief resulting from their children's severe mental illness (Richardson et al., 2013).

Limitations included a small sample size that limits the generalizability of findings (Richardson et al., 2013). Also, participants were mainly mothers and these results may not capture or accurately describe the experience of fathers of children with severe mental illness. Because participants did not have to meet specific eligibility criteria, their children ranged in type of psychopathology and some had comorbid developmental disabilities. Because type of diagnosis was not controlled for, the impact of different diagnoses on parents' levels of loss and grief cannot be stated. Lastly, parents' own history or current psychopathology was not controlled for, which may also impact their functioning and coping with loss and grief related to their child's mental illness. Richardson et al. (2013) recommend that future research should focus on fathers' experiences while targeting various populations. Studies should also examine if parental grief is affected by characteristics of their child's illness, such as diagnosis type and severity, as well as parents' past or present psychological functioning.

Ahmann (2013) proposed a novel idea – to explore how parents make meaning of their child's diagnosis. Ahmann (2013) conducted in-depth interviews with four mothers about how they found and created meaning from the experiences resulting from their children's mental health diagnoses. Mothers interviewed spoke to a wide range of

persistent mental illness; one interviewee was the mother of an adolescent girl who was diagnosed with attention deficit/hyperactivity disorder (ADHD) inattentive type while another was the adoptive mother of a son who was diagnosed early in his infancy with reactive attachment disorder. The other mothers, two sisters, were each parents to multiple children, all diagnosed with mental illness. One sister had a daughter with Asperger's syndrome and another daughter with a non-verbal learning disability while the other sister had three children, one diagnosed with ADHD and another eventually diagnosed with bipolar disorder (Ahmann, 2013).

All four mothers, despite their unique and individual experiences, described themselves as feeling helpless as their children suffered with symptoms of mental illness (Ahmann, 2013). However, each was able to somehow make meaning of their experience. Mothers were both personally benefitted from their ability to make meaning and able to positively impact other parents. Two emergent themes from their interviews were finding purpose and making meaning through helping other parents and by growing as a result of helping others. Meaning making was accomplished in a variety of ways by each mother including developing and disseminating educational materials via websites and pamphlets; connecting and consulting with doctors and educators; writing a light-hearted, non-clinical book about children with special needs; participating in and leading speaking engagements and support groups; and coaching and leading parenting groups. Even with these apparent resiliencies, mothers still reported experiencing negative feelings such as hurt, pain, and anger (Ahmann, 2013). These self-reports indicate that future research should investigate lingering negative feelings experienced by parents despite their ability to make meaning of their children's mental illness diagnoses. These

results highlight that even when parents are able to reframe a seemingly negative event into a positive, meaningful one, negative and unresolved feelings may be lurking in their psyches. Accordingly, all parents, even if they perceive they have fully accepted their child's fate, and their reports of experiences would be beneficial for understanding experiences of parents who are in different stages of grieving. This also speaks to the fact that grief symptoms may always be present in the caretaking parent.

Given these very recent and limited findings, it is imperative that more research be conducted with younger parents of non-adult children with mental illness. Although their experiences seem to align with experiences of parents of adult children with severe mental illness, symptoms of loss and grief may be more profound since a child being diagnosed younger may be viewed as more tragic, more of a loss due to less time spent with the child they once knew, and earlier diminishment of aspirations for one's child.

Purpose of the Present Study

The current exploratory study aimed to investigate the experience of parents whose adolescent children have severe and persistent mental illness. The aim was to better understand these parents' experiences by conducting qualitative research in which parents could express their experiences of having children who have been diagnosed and treated for severe mental illness. The goal was to identify what types of experiences were prominent for these parents and to see if the current sample expressed ones similar to those found in past research; If loss and grief was a prominent experience for these parents, the present study aimed to identify the types and impacts of losses that characterize their experience. Along with this, the researcher hoped to better understand whether some of the issues raised in the grief literature – such as avoidance,

hypervigilance, and re-experiencing experiences in addition to feelings of subjective and objective burden – may also apply specifically to parents of adolescent children with mental illness.

A major hope of this study was to identify the presence of and expand the understanding of the experiences of grief, trauma, objective, and subjective burden in parents whose non-adult children have severe mental illness. Currently, there is no extant literature that examines traumatic reactions in parents who have children with severe mental illness. Halpern and Tramontin (2007) defined psychological trauma as "an emotional wound or shock of lasting effect" (p. 4). Research indicates that grief among parents with children who have severe mental illness is cyclical in nature, and chronic in that there is no identifiable end point to the crises or to the reaction (Penzo & Harvey, 2008; MacGregor, 1994).

In disaster psychology, a person's reaction is shaped by the person's existing resiliencies and vulnerabilities, one's current and past psychological history, the social and communal support felt by the person, the person's proximity to the disaster and his or her response, and the lasting effects of loss or stress the person feels afterwards (Halpern & Tramontin, 2007). These qualities could easily be applied to parents who have children with severe mental illness, and should be used to examine the presence of trauma symptoms in these parents. Given that these parents' grief reactions are unremitting, they are usually defined as complicated grief. Complicated grief may be similar to trauma experiences, in that people re-experience the loss through intrusive thoughts, but may not experience the same levels of anxiety as those who have PTSD and re-experience a traumatic event. People who experience traumatic reactions and complicated grief may

also experience avoidance of social activity and interpersonal relationships, hypervigilance in searching for their lost loved one, and hyperarousal in persistently longing for their loved one (Halpern & Tramontin, 2007).

Many of these symptoms of avoidance, hypervigilance, and hyperarousal have been noted in previous research, but have been used as markers of grief rather than as traumatic reactions (Cook, 1988; Davis & Schultz, 1998; Dore & Romans, 2001; Godress et al., 2005; Howard, 1994; MacGregor, 1994; Mohr & Reagan-Kubinski, 2001; Penzo & Harvey, 2008). The goal of identifying these symptoms in parents of children with severe mental illness is to better parse traumatic symptoms and grief, and thereby to gain a better understanding of the distinction of each construct, as well as to fill the gap in the current literature. Accordingly, it is hoped that by qualitatively exploring this aspect of the parental caregiving experience will create a foundation upon which future research may quantitatively validate the presence of traumatic symptoms in caregivers. The intent of exploring the traumatic symptoms experienced by caregivers may contribute as evidence for future research focused on better differentiating grief reactions from traumatic reactions.

Therefore, a qualitative investigation was conducted utilizing strategies of consensual qualitative research described by Hill, Thompson, and Williams (1997). The purposes of the study were to explore the experiences of parenting an adolescent with severe mental illness and to identify related concepts generated by the participants. A semi-structured interview that utilized open-ended questions based around the concepts of grief, loss, burden, and emotional and cognitive reactions was employed for the purposes of this study.

CHAPTER II

METHOD

Participants

Participants were conveniently sampled from online support groups, a mental health organization's newsletter, by word-of-mouth, and by advertisements posted in one university's community. Participants were informed in the recruitment advertisement that they must be at least 18 years old, the custodial parent or caregiver of an adolescent child (aged 13 to 17 years) diagnosed with a severe and persistent mental illness, and English-speaking. For the purpose of this research, a custodial parent or caregiver was defined as a person who assumes responsibility for a non-adult child, including biological parents, relatives – such as grandparents, adoptive parents, and stepparents – and legal guardians. For the purposes of this research, severe and persistent mental illness was defined as any diagnosis in the following categories, as defined and outlined in the *Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-V;* APA, 2013): Schizophrenia Spectrum and Other Psychotic Disorders; Bipolar and Related Disorders; Depressive Disorders; Anxiety Disorders; Obsessive-Compulsive and Related Disorders; Trauma- and Stress-Related Disorders; Dissociate Disorders; Somatic Symptom and Related Disorders; Feeding and Eating Disorders; and Disruptive, Impulse-Control, and Conduct Disorders. Additionally, caregivers were informed their child must have: at least one diagnosis that fits into one of the above categories, been diagnosed at

least six months ago, been diagnosed by a medical or mental health provider (e.g.,

general practitioner, psychologist, psychiatrist, social worker, counselor, nurse

practitioner, physician's assistant, or other related providers), and currently be receiving

mental health services.

Initially, 17 individuals emailed the principal investigator to indicate their interest

in participating in the current research study. A total of 13 custodial parents (10 women,

3 men, M_{age} = 45.38 years, SD_{age} = 9.65 years, age range: 25 - 60 years) participated in

this study. Four potential participants were excluded; Two potential participants did not

meet participation requirements (i.e., their children were not between the ages of 13 and

17 years old), one had an ongoing scheduling conflict, and one did not respond to follow-

up emails after her initial email. Of the 13 individual participants, nine (69.23%) self-

identified their race as White, two (15.38%) as Hispanic, one (7.69%) as Alaska Native,

and (7.69%) one as Native American. Participants were comprised of nine biological

mothers, two biological fathers, and two legal guardians. Of the two legal guardians, one

was the child's biological grandmother who adopted the child nine years ago and the

other legal guardian (male) was not biologically related. Two of the participants were

married and were separately interviewed about their experience of their adolescent child.

One participant had two adolescents who both fit the research study criteria so she

discussed both of her children throughout her interview.

A total of 13 adolescents were discussed in relation to parental experiences (nine

girls, four boys, M_{age} = 14.92 years, SD_{age} = 1.32 years, age range: 13 – 17 years). Each of

the adolescents had received at least one of the following diagnoses: Obsessive

Compulsive Disorder (5), Major Depressive Disorder (3), Major Depressive Disorder

with mood congruent psychotic features (1), Posttraumatic Stress Disorder (1), Conduct

Disorder (1), "depression" (4), Generalized Anxiety Disorder (1), "anxiety" (3),

Attention-Deficit/Hyperactivity Disorder (4), Oppositional Defiant Disorder (1),

Anorexia (1), and Eating Disorder Not Otherwise Specified (anorexia; 1). The teenagers

had been diagnosed anywhere from 6 months to 10 years before the date of their parents'

interviews ($M = 3.40$ years, $SD = 2.71$ years) and had been receiving some type of mental

health treatment anywhere from six weeks to eight years ($M = 3.12$ years, $SD = 2.23$

years). Adolescents had been diagnosed by the following types of practitioners, per

parents' reports: MSW, LCSW, MD, psychologist, psychiatrist, pediatrician, and LMFT.

Adolescents were currently in treatment with the following types of practitioners, per

parents' reports: MSW (1), LCSW (1), psychiatrist and psychologist 4), psychologist (1),

pre-doctoral psychology intern (2), psychiatrist (1), LCSW and psychiatrist (1), school

counselor (1), and a forensic psychologist (1). Of these adolescents, 50% had been

hospitalized or inpatient at one point in time.

Instruments

A semi-structured interview, adapted from an interview created for and utilized in

previous research (Richardson et al., 2013), was used to assess cognitive, behavioral, and

emotional components of parents' experiences of their children's mental illnesses (see

Appendix C). This interview consisted of 32 open-ended questions that assessed parents'

initial response to their children's diagnoses as well as their current response in a

confidential and anonymous way. Parents' perceptions of social support, coping, stigma,

and access to care were queried as well. Example questions from the interview include

"When you were first told by a health professional (such as a psychologist, general practitioner, social worker, or psychiatrist) that [*young person's name*] has a mental health condition, what was that like for you?" and "What, if any, have been some of the challenges for you as a parent of a young person with a mental health condition?" The beginning of the interview consisted of closed-ended demographic information questions as to gently introduce participants to the interview process before introducing more sensitive questions (Hill et al., 1997). A digital audio recorder was used for the purposes of recording interviews so they could be transcribed afterwards.

Procedure

Sample Development

A recruitment advertisement (see Appendix A) was used to solicit potential participants. The advertisement informed recipients of the research topic, participant requirements, and their right to withdraw from the study without penalty. The advertisement included that the Institutional Review Board at the University of North Dakota had approved the research study, and the email address to be used to contact the principal investigator. Participants signed and were given a copy of the informed consent document (see Appendix B) that outlined the aims of the project and the rights of research participants. The recruitment advertisement was posted to topic-pertinent Facebooks pages, sent by email to related listservs, and posted in the campus community of a midsized Midwestern university. The recruitment advertisement contained the principal investigator's email address and interested participants emailed the principal investigator to provide their phone number. The principal investigator called these potential participants to ensure each participant met all requirements for eligibility and to

schedule an interview date and time. The investigator emailed a copy of the informed

consent document to participants so they could read, sign, and return the form

electronically before engaging in an interview. Parents who participated in interviews

were recruited via word of mouth (53.85%), from online support groups (30.77%), and

from an organization's newsletter advertisement (15.38%).

Data Collection

Each interview was conducted via telephone and was audio recorded for the

purposes of later transcribing and analyzing participant responses. Participants were

provided information orally and in writing about the research purpose, the tasks, the

length of time the interview was expected to last, the session being audio recorded, and

their right to withdraw their participation or data at anytime without loss or penalty. They

signed and returned the informed consent form via email, indicating their informed

consent. Telephone interviews were conducted while the interviewer was in a private,

confidential office space. Participants were informed that the researcher could not ensure

complete confidentiality on their end if they engaged in telephone interviews, and

confidentiality was dependent on the environment in which the participant spoke.

After informed consent was acquired, each parent completed a qualitative

interview, initially estimated to take about 60 minutes. On average, interviews were

approximately 80 minutes (range: $23.5 - 114$ minutes, $SD = 23.56$ minutes). All

interviews were conducted by the principal investigator. The principal investigator can be

briefly described as a White female counseling psychology doctoral student. After

completion, participants were thanked and were given contact information for the

researcher and the Institutional Review Board. Participants were given the option to

review the transcript of their session after transcription. All participants indicated they wanted to review their transcript and also be sent the final results of the project to see how results fit with their individual experiences. Only one participant made a change to her original transcript in the form of adding a comment to the last question.

Analysis Team

A qualitative methodology was employed for this study. Themes in the parents' interview responses were uncovered using Consensual Qualitative Research (CQR; Hill et al., 1997). CQR is a qualitative process in which participants are viewed as experts of their experiences and researchers gain insight into phenomena by learning and garnering meaning from participants. Core components essential to CQR include interviews utilizing open-ended questions, relying on verbal descriptions rather than quantitative measurement, a small sample, understanding the context of participants' experiences, relying on inductive methods and processes, coming to consensus of opinions and judgments of three to five researchers, utilizing an auditor, and cross-checking findings with raw data to ensure valid conclusions. CQR is comprised of three steps: each participant's responses are divided into domains, brief summaries are created for the responses within each domain for each participant, and a cross analysis in which categories are developed to describe consistencies in core ideas across cases is created (Hill et al., 1997).

Because data was analyzed and interpreted by a diverse team, the following description of each research team member is provided. Sloan Henry is a third-year master's student emphasizing in community mental health from the Turtle Mountain Band of Chippewa Tribe. She is 34 years old, has been married for 12 years, and is the

mother of four children ages 7, 9, 11, and 14 years old. Her clinical focus is working with

Native Americans specifically around families' trauma, elder abuse, and domestic

violence. Rebecca Ruggles is a third-year master's student emphasizing in community

mental health of European descent. She is 25 years old, is married, and is the mother of

two children ages 4 years and nine months old. She currently works with families and

individuals who have experienced trauma. Megan Sys is of European descent and is a

first-year master's student emphasizing in school counseling. She is 23 years old. Lindsay

Yates is of European descent and is an advanced doctoral student and principal

investigator. She is 27 years old and is married. She currently works in an isolated

hardship site with Alaska Native individuals and families.

Before reading transcripts and beginning the analysis portion of the project, all

research team members attended a meeting and were trained in the CQR process by the

principal investigator. Team members were also provided a tentative schedule for

research team meetings and deadlines. When analysis commenced, each research team

member had read some segment of the interviews that were transcribed by the principal

investigator. Prior to beginning the coding process, the team acknowledged existing

assumptions. Therefore, each person made a written list of assumptions in an attempt to

discuss them with the team as an effort to limit their impacts on data analysis.

Assumptions fell into two general categories: assumptions based on knowledge of

treating adolescents with mental illness (including biases about medication) and

assumptions based on personal experiences of parenting or having close family members

who are parenting non-adult children. In making biases and assumptions explicit and

discussing them within the group, the team attempted to avoid interpretation and developing themes and categories from preconceived notions when analyzing transcripts.

The research team met twice per week to discuss individual coding of the data in order to move toward group consensus about the data. Each meeting was held via telephone. Attempts to make the group more egalitarian were taken including rotating which team member would lead the discussion for each question. The team attempted to encourage and incorporate feedback from each group member as equally as possible.

Identification of Domains

One case (Case 4) was randomly selected to be the first transcript for which researchers independently developed domains (Hill et al., 2005). Another case (Case 8) was randomly selected to be the last transcript all research team members would read and analyze independently before coming together as a group to come to consensus. All researchers then came together to assess if each team member was approaching the task similarly. After the similar approach styles were verified, the team split into two pairs. One pair read Cases 1, 2, 6, 7, and 11 independently and came to consensus. The other pair read Cases 3, 5, 9, 10, 11, and 12 independently and came to consensus. Finally, Case 8 was analyzed independently by each team member and a consensus meeting was held. Each transcript was read and blocks of data were assigned to a domain (or two, if appropriate). Once a consensus was reached on appropriate domain titles, a consensus version of the transcripts was created, therefore leaving original interview transcripts unaltered (Hill et al., 1997). The initial analysis yielded a list of 82 domains.

Core Ideas

Next, each research team member independently summarized the data in each

domain into core ideas (Hill et al., 1997). Once the core ideas were created

independently, the members reconvened to come to consensus on the core ideas. All the

while, research team members kept records of their impressions and reactions to each

case. This helped to parse researcher bias and reactions from those of the participant.

Domains and core ideas were listed in an Excel spreadsheet with three pages. The first

page listed all possible domain names in column A and transcripts in row one with team

members placing an "X" if the domain was identified in each transcript. The second page

listed all domains in column A and each core idea of the respective domain in an

independent cell horizontally in its corresponding column. The third page allowed

researchers to list the transcript and line numbers in corresponding cells from page 2 to

help identify specifically where each core idea was found in each transcript. Examples of

core ideas included: parent-child, current support, challenges to support, grief, seeking

treatment, parenting challenges, and understanding of diagnosis.

Audit of Domains and Core Ideas

After consensus of the core ideas was reached, the auditor was given a master list

of domains and core ideas from the 13 transcripts. The auditor read samples of all the

transcripts and identified how examples/lines of texts fit into domains, looked through the

lists of core ideas and domains, and looked at potential themes across domains and core

ideas. The auditor gave her comments back to the team, who then met to discuss and

implement feedback (Hill et al., 1997). The auditor, Dr. Cindy Juntunen, was the

dissertation chair of the principal researcher and did not participate in the interview or

analysis portions of this project. Dr. Juntunen is a faculty member of European descent whose interests are career psychology and multicultural relationships. The audit resulted in the team's verification, clarification, and combination of many domains and core ideas initially identified by the team. The post-audit discussion of the team resulted in the development of a smaller number of higher-order domains that more meaningfully included major core ideas.

Cross Analysis

After this, the cross-analysis took place (Hill et al., 1997). The team evaluated whether or not there were similarities across cases. This examination was furthered by inspecting all core ideas within domains and grouping them in categories. Categories were then evaluated as to how well it represented the sample (e.g., general, typical, variant, or data was dropped). Finally, the auditor reviewed the cross analysis and sent her comments to the team for implementation. The auditor reviewed domains and core ideas and commented that she did not find any inconsistencies in the supporting documents of exemplar quotes/lines but that core ideas could be pared down. The team reviewed the data and condensed several core ideas and deleted several miscellaneous findings. This prepared data results to be written up. When results were written they were sent to all participants who had endorsed during their interview wanting to see final results.

CHAPTER III

RESULTS

The purposes of the study were to explore the experiences of parenting an adolescent with severe mental illness and to identify related concepts generated by the participants. A qualitative investigation was conducted utilizing strategies of CQR (Hill et al. 1997). A semi-structured interview that utilized open-ended questions based around the concepts of grief, loss, burden, and emotional and cognitive reactions was employed for the purposes of this study. This chapter contains an explanation of the domains and core ideas in each domain, exemplar quotes of each core idea, and the qualitative descriptors for each domain and core idea. Qualitative descriptors provide information on how prominent each theme and idea was amongst participants and are defined as follows: "General" for results that were found in all 13 cases, "Typical" for results that were found in at least half (7) of cases, and "Variant" for results that were found in at least two but less than half (2 to 6) of cases.

An in-depth analysis of each transcript and cross analysis of transcripts yielded seven domains: Impacts; Evolving Behaviors, Feelings, and Attitudes; Relationships; Treatment Experiences; Understanding; Supports; and Barriers. Within each domain, core ideas were created from the data. The following paragraphs outline each domain and its core ideas. See Table 1 for a comprehensive list of domains, core ideas, and their qualitative descriptors.

Table 1. Domains, Core Ideas, and Qualitative Descriptors.

Domain	Core Idea	Qualitative Descriptor
Impacts	Effects on family	General
	Violence towards others	Typical
	Violence towards self	Typical
	Violence experienced by parent	Variant
	Negative social consequences	Typical
	Parenting challenges	Typical
	Majority of caregiving responsibility	Variant
	Impact on adolescent	Variant
	Legal consequences	Variant
	Health impact	Variant
Evolving Behaviors, Feelings, and Attitudes	Personality traits	General
	Changes	Typical
	Initial onset	General
	Symptom changes	Typical
	Reactions	General
	Loss	General
	Grief	General
	Triggers	Variant
	Intrusive thoughts	Variant
	Reflections on the past	General
	Subjective experience	General
	Parents' thoughts of the future	General
	Expectations	Variant
	One day at a time	Typical
	Moving on	Variant
Relationships	Parent-child	Typical
	Child-peers	Variant
	With others	Variant
	Child boundaries	Variant
Treatment Experiences	Treatment experiences	General
	Parental enactment of treatment	Typical
	Treatment challenges	Typical
	Seeking treatment	Typical
	Adolescent attitudes toward treatment	Variant

Table 1. cont.

Domain	Core Idea	Qualitative Descriptor
Understanding	Family history	Typical
	Roles of parents	Typical
	Understanding of diagnosis	Typical
	Pre-existing understanding	Typical
	Understanding prognosis	Variant
	Context	Variant
	Comparison	Typical
	Attribution	Typical
	Lessons learned	Typical
Supports	Current support	General
	Supports wanted	Typical
	Potential advice for other parents	Typical
	Empathy	Typical
	School supports	Variant
	Self-help	Variant
	Self-care	Variant
	Advocacy	Variant
	Supporting others	Variant
Barriers	Finances	Typical
	Challenges to support	Typical
	Stigma	Typical

Note. The qualitative descriptors are defined as follows: "General" for results that were found in all 13 cases, "Typical" for results that were found in at least half (7) of cases, and "Variant" for results that were found in at least two but less than half (2 to 6) of cases.

Impacts

According to the parents interviewed, there were daily and prolonged impacts on both parents and their children due to the children's mental illness. Additionally, consequences were felt by the family. These effects manifested in areas of social, legal, and health functioning among parents and their children. These felt effects emerged as a

general domain titled *Impacts.* Core ideas included effects on family[1], violence toward others[2], violence toward self[2], violence experienced by parent[3], negative social consequences[2], parenting challenges[2], majority of caregiving responsibility[3], impact on adolescent[3], legal consequences[3], and health impact[3].

In all interviews, the effects on the family were discussed. These consequences were seen in relationships and interactions of the child with family members, effects on siblings including the parent losing time and energy to give equal attention to other children, affecting the parent potentially looking for a romantic partner, the child's symptomatology creating tension and stress in the household, dissolving guardianship due to career-related jeopardy, interfering with making firm commitments in the future, having the child removed from the household while in acute or residential treatment, impacting daily scheduling due to consideration for making additional appointments, feeling uncomfortable leaving the child home alone or without one parent present, fear that siblings will cope in ways that are harmful due to knowing the child engaged in self-harm, increasing communication amongst family members, members of close-knit families feeling distraught over the child's mental illness, attempting to maintain normalcy and stability, perceiving the parent and child roles to have reversed leaving the parent feeling powerless, interruption of engaging in activities as a family, spousal stress due to disagreements about decision making related to the child, siblings feeling like they don't actually have a brother or sister in the identified patient, increasing arguments and yelling in the household, restructuring the careers – sometimes including out-of-state

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[1] General

[2] Typical

[3] Variant

moves – of parents to accommodate caretaking of the child, changing sleeping arrangements, and trust being broken and safety and security in the home feeling compromised. A father spoke to how his family has been affected by his son's mental illness:

> *…it impacted our day-to-day life where, "We can't leave him alone in the house. How do we get his brother to school?" And how can we make it so my wife can actually leave the house for periods of time if I'm at work? And do I… I mean I looked into the possibility of taking a leave of absence from work because it's just like when you basically have a 12-year-old that you can't leave alone it's highly disruptive. I think that other than that just kind of the scheduling of things, of not really being comfortable to commit and so forth.*

Parents recollected the experiences of if their child had been violent toward others. Parents' reports varied from absolutely no violence toward others, verbal aggression and threats, violent outburst of destroying property, and violence toward others. Some of the violence was characterized as unintentional, like an accidental blow to someone while the child was symptomatically activated, whereas some of the violence was characterized as aggressive, intentional acts toward others including siblings. One mother discussed her daughter's physical and verbal violence toward others:

> *Yes. For a very long time she was extremely violent to her eight-year-old brother, who was at that time six and seven. So, screaming at him incessantly and she would jerk him up by his arm and I mean he's a scrawny little kid so she could just fling him across the room. And throw things at him and just, you know, punch him, kick him. So a lot of times that was one of our issues was dealing with that*

and how to make her stop that because it wouldn't even be anything he'd

necessarily done, she would just get angry with him and fly off the handle and just

take it out on him. And then just anger with other people. Not necessarily physical

violence but verbal. Very, very verbal with everybody. Just verbally violent, just

screaming, "I hate you. I don't want to live with you. I don't want to be around

you." Everybody was "horrible," "everybody was "hateful," everybody hated

her. And just extremely… to me, my parents, my sister… just extremely verbally

aggressive to everybody.

Parents talked about the experiences of if their child had been violence towards themselves. Parents' reports varied from no violence toward their child's self, their child engaging in self-injury intentionally and unintentionally (e.g., obsessive fingerpicking), suicidal threats, and punching themselves or head banging. One mother discussed her daughter's physical violence toward herself:

…her thing is she'll punch herself in the stomach really hard over and over again.

One time she started hitting her head on the floor really hard… but it's more

intense when she's punching herself in the stomach that's very like, "I want to

hurt myself." And she has said a number of times, "Well I'm going to kill myself."

Parents elaborated about their experiences of experiencing violence from their children. Parents' reports varied from experiencing no violence from their child, to having thoughts of if their child ever attempted to be violent toward them, to feeling personally victimized when they see evidence of past violence such as broken furniture or walls, to experiencing physical and verbal violence from their child. Parents reported

both intentional and unintentional violence from their children. One mother recalled her experience of physical violence from her daughter:

> *One time after her therapy appointment, I guess her psychologist had her do*
> *something that was like really high on her hierarchy and she was really upset and*
> *I was telling her to stop and stop and then she punched me in the arm. Oh my*
> *God, I felt angry. At the same time, I felt so helpless because I was driving on the*
> *highway. And it's not like I could just stop. So I just wanted to get home. And I*
> *was crying the whole ride home. It's like you've lost all control of your child.*

Other parents discussed the negative impacts on their social lives due to the unpredictability of their children's symptomatology. Parents described changes in their social life to include having difficulty having conversations with other parents, losing peers or feeling distance from friends who used to be closer, disengaging in committing to social plans with others, feeling gossiped about, declining social invites due to exhaustion, isolating due to avoiding others and talking about themselves, deleting social media, staying in because the child didn't want to go out and could not be left alone, not wanting others in their homes, and feeling as if friendships that "could have been" were not formed. One mother discussed the negative social consequences she has experienced:

> *Socially I don't want to have anyone over to our house because I don't know what*
> *could happen, also there's a lot of… Like I said, home is where she lets*
> *everything out, so there's all kinds of little things about being in our house that*
> *are kind of odd. And then I'm just so exhausted that it's the last thing I want to do*
> *is have a dinner party or something. And I don't feel great about leaving her. It's*

a weird thing, too, because she's too old to really have a babysitter now but I

don't feel great about leaving her by herself, so that limits our social stuff too.

In numerous interviews, parents discussed the various challenges they face as a parent of a child or children with mental health issues. Challenges reported included feeling clueless of what questions to ask or how to talk with their child, difficulty focusing on the parent's hopes and dreams, the child running away from home and acting out, parents questioning their parenting abilities, feeling unprepared and out of control, invalidation from professionals, feeling overly-responsible, coping with their own emotional reactions, navigating the legal system, not knowing when to discipline or hold their child responsible, wondering how to advocate for the children in the best way, struggling to bond with the child, anticipating negative consequences for the child, feeling the need to constantly watch the child and losing peace of mind, talking to siblings and/or family about the child's mental health issues or treatment, implementing therapist advice that does not work, and resisting the urge to physically strike the child. One mother spoke to her experience of facing ongoing challenges:

I mean it's a constant… I feel like we're constantly watching and making sure and

trying to make sure she's eating what she needs to and making sure she's doing

things that she needs to and making sure that she's taking her medication and

making sure that she's hanging out with the right people. Just, I feel like we're

keeping constant watch over her.

In several interviews, parents discussed they felt sole responsibility for caregiving for their child, either due to necessity of being a single parent or because of a perceived unequal responsibility distribution within a spousal relationship. Parents spoke of this

responsibility to include pressure to work and provide leaving no time for constant monitoring of their child, feeling as if children gravitate toward one parent of the same sex, having to do most of the planning and coordinating for children's activities, feeling pressure to keep a child from returning to a previous home placement or family, feeling burdened and unacknowledged, being a single parent or feeling like a single parent even if partnered, having to make decisions without input from the child's other parent, feeling like the problem solver and holder of hope for the child, and feeling the parent is the only one who should and know everything. For example, one married mother spoke of her experience:

> *And that's part of, for at least me personally, what's been hard is feeling like within the family dynamic I may be the only one who knows everything but I feel like I need to be the only one who knows everything but that also means that then I'm also the only one that's kind of dealing with it. So that's kind of like a huge burden and very lonely… it's not like [child's name]'s parents are dealing with it. It's like [child's name]'s parent is dealing with it. I just have to internalize it, have my view, there's not really anyone to like bounce it off like, "Hey am I overcompensating? Do I need to back off a little bit?"*

Interviewees discussed the idea of how their adolescent had been impacted by their mental health diagnoses. Impacts were both positive and negative and included shaping children's career goals, detracting from the child's sense of childhood and cohesion amongst the family, the child feeling mentally restricted and unable to fulfill full intellectual potential due to necessary medication, symptomatology serving as a roadblock to high achievement in school, the child needing extra support to cope with

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daily situations and experiencing others as having it easier, adding a sense of daily struggle, and being at the mercy of symptomatology. One mother described her experience of witnessing the impact of mental illness on her daughter:

It's really intense to kind of watch that and almost experience it because she's right next to me and I'm watching everything going on with her but I literally can't do anything because when she's in the throes of it she's not responsive to me, she's just kind of in her own head and it's not like I can just take away the pain or do something to help her.

In several interviews, the possibility of potential or the experience of previous legal consequences were discussed. Parents varied in their reports from those whose children had not experienced legal consequences to one whose child was incarcerated at the time of his father's interview. One mother reflected on the monetary effects of her son's truancy:

I've had to pay all these fines, like the $2,000 fine I'm paying because he quit going to school and was out of school most of last year. And apparently I've got a $2,000 fine compliments of the school here in [city name] that I have to pay.

Other parents also discussed the negative physical and mental health impacts they have and continue to experience. Parents discussed having pre-existing mental health issues that were exacerbated by their children's symptomatology and either re-starting or having their current medication adjusted, gaining weight and feeling overall less healthy, experiencing somatic symptoms from anxiety such as gastrointestinal problems and interrupted sleep, and developing new stress-related physical health conditions. One mother described her health declination:

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One of the things I've experienced, which I don't know how much of it is tied up

with what happened with [child's name] but I'm pretty sure it's largely

connected, is I am at the beginning stages of Lupus, which is an autoimmune

disorder. And what I know of autoimmune disorders is there's a genetic

predisposition, which my had has rheumatoid arthritis which is related to it, and

there's also an emotional/physical piece to it. I know a lot of women from a

domestic violence situation end up with an autoimmune disorder and I don't want

to at all compare it to that because I think that's a different thing, but in a way it's

very similar because there's a lot of fear and shame and watching my child

basically be abused by herself and the way she lashes out at me and kind of not

being able to talk to people about it and keeping it all inside all the time. I think

that that has definitely taken a huge toll on my body. I think my adrenal glands

are kind of shot and my body… I just feel like extremely fatigued all the time and I

just think a lot of that is because I'm holding all of that inside all the time, and

again being that strong support person where it's like she can freak out and start

screaming and do all this stuff, but that's totally unacceptable for me to do as her

parent and as a support person in her life.

Evolving Behaviors, Feelings, and Attitudes

According to the parents interviewed, there were prominent changes that occurred in their child's personality, symptomatology, parents' subjective experiences and outlooks, and parents' reflections on the past to current thoughts and outlook on the future. These past to present changes emerged as a general domain titled *Evolving Behaviors, Feelings, and Attitudes.* Core ideas in this domain included children's

personality traits[1], changes[2], initial onset[1], symptom changes[2], reactions[1], loss[1], grief[1], triggers[3], intrusive thoughts[3], reflections on the past[1], subjective experience[1], parents' thoughts of the future[1], expectations[3], one day at a time[2], and moving on[3].

All parents interviewed described their children's personalities. Children's personalities were various and included descriptors such as sweet, socially outgoing, eager to please, anxious, humorous, strong-willed, irritable, emotional, lacking patience, introverted, nice, unhappy, testy, spiteful, driven, engaging, lacking empathy, quiet, and helpful. One father described his daughter's personality:

> *She's very introverted, to herself. I don't know… she gets excited when you talk about things that are of interest to her, I guess like most people do, like music and movies and directing. She's very emotional. I think she definitely wears her heart on her sleeve. Quick to get upset when things don't go her way. Doesn't seem to have a lot of patience in her. Very short-sighted. I don't think she's kind of grasped the whole idea of looking at the big picture. She's a teenager, I guess.*

In many interviews, parents discussed changes they noticed in their children or in their overall experience. These changes included a shift from a tough to an easier experience, changing schools, changing personalities, changes in relationships, and changes in outlook for the future. One mother described how she experienced a sudden change in her and her son's life:

> *He was set up for success. He was the one I had expected so many great things out of and it just turned to shit and it's very disappointing. I used to love going to*

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[1] General
[2] Typical
[3] Variant

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the ballgames when he played football and rooting him on. And I loved going to

the Boy Scouts stuff. I was very involved. And I was so proud of him when he

would make these accomplishments. And then all of a sudden it stopped and it's

like, "Well." Even after we got here, I tried to get him in the rec room or the

ROTC or something but all he wanted to do was hang out with trashy kids and

roam the streets and smoke weed and not go to school.

Parents recalled when they first noticed their children's symptoms. Initial onset experiences included noticing stereotypical symptoms of diagnoses, their child voicing fears, the child experiencing a traumatic event, perfectionism in school, noticing changes in personality and behaviors, being informed either by the child or another adult of the child's threat to hurt herself or someone else, withdrawing from friends and family, finding worrisome text messages in the child's phone, and noticing external evidence such as going through bandages quickly or blood on clothes or bedding. One mother recalled the initial onset of her daughter's mental illness:

…and [child's name] just happened to start when she was eight-years-old with

the hand washing, and this is such an overly-typical symptom of OCD. She just

kind of started spending a lot of time at the sink and washing her hands nonstop,

saying they weren't clean enough, she had to go back and do it again, and with us

being so close I was frequently around her so I noticed that right away…

Interviewees also discussed their children's changes in symptomatology. Changes included symptoms remitting, symptoms increasing or becoming exacerbated, symptoms creating and contributing to other mental health disorders, symptoms appearing in

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different and in more contexts, and the cyclical nature of symptoms. One mother commented on the changes she has seen in her daughter's symptoms:

Now that she's come out of the hospital she is… unfortunately her roommate in the hospital was bulimic and so now [child's name] is back on the thing where she's got this body issue image again where she feels like she's overweight, so she's lost… She was up to 108 pounds and now she's lost, she's back down to I think 104. So, we're… she's kind of on that downslide I feel like where she's got this body image issue again. So, she's not currently cutting and the depression is getting better but I feel like she's just taking that cutting mechanism, the coping with that, and just turned it into coping… using another thing to cope with.

All parents interviewed discussed their reactions to a variety of issues including initial onset of children's symptoms, diagnosis, treatment options, current functioning, thoughts of the future, and the responsibility of being a caretaker. Parents reactions included wanting to help, worry, shock, fear, anxiety, relief when their child was diagnosed, optimism, pride, thankfulness, cognitive dissonance, denial, hopelessness, sadness, helplessness, validated when their child received a diagnosis, unprepared, regret, anger, frustration, doubt, mixed, overwhelmed, responsible, guilty, disappointed, and hopeful. One mother described her conflicting reactions:

Some days I feel really proud of her and really hopeful and like, "Yeah, she's got this!" and "Things are good." And other days I don't know what to do and I feel really helpless. So, it's a really interesting mix of emotions for me right now. In talking about it, I would say my anxiety goes up. I start feeling anxious, I would almost say there's a little PTSD in there just because when I start thinking about

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it, it brings up all these emotions that I've experienced of fear, anxiety,

frustration, like, extreme frustration, helplessness. And when I talk about it that

all starts coming to the surface again.

All interviewees were asked if they had experienced loss as a result of being a parent of a child or children with severe mental illnesses. Some parents denied experiencing loss while others endorsed experiencing loss currently, experiencing loss in the past, experiencing loss accompanied by great sadness or sorrow, experiencing loss in relation to understanding mental illness as lifelong and potentially leading to suicide, experiencing loss before their child was diagnosed, and experiencing loss due to feeling helpless. One mother elaborated on her experience of feeling loss concerning her son:

Yeah, because I knew that no matter what he was never going to be the old

[child's name]. There was a sense of loss because when something traumatic like

that happens to anybody you're never the same. It felt hopeless, very much so.

Parents discussed the presence and experience of grief. Some parents reported they experienced grief in the past but none currently, never experienced grief, or were currently experiencing grief. One father spoke of the grief he experienced in relationship to his son:

Yeah, a lot. I would say since the first episode I feel like every time I have to

mourn this part of [child's name]and at the same time I have to go through

everything. I go through anger at him, anger at myself, and I have to eventually

come around and accept that it's not the caretaker's fault. And so it's something

that it's just there because there's some trauma in all of that. And I have to accept

that it's there and then I go through everything and then when he gets back into

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one of those phases, or then like currently when I think about it all the time, I

immediately go back to, "He's gone. This part of him is gone." I get angry. I find

myself all the time trying to, it's the codependent part of me but, when he calls me

and he's like, "I want to get out of her." I go through it and I'm like, maybe in my

brain I don't say it but my brain goes through it, like, "Maybe it was just the

adjustment period and now it's different. Maybe now he's better." And it's the

same thing as bargaining in my opinion. It's like, "Maybe it's going to be

different this time." And then it's not because I know it's not. It's his diagnosis. I

definitely feel like I'm always, I constantly have to grieve and mourn him every

time something happens.

Some of the parents interviewed identified times of the year, experiences, items, and/or smells that served as triggers either to parents themselves or to their children. Examples of triggers included activities, smells, clothing, school starting, anniversaries, memories, holidays, going back to a certain place, and peers. One mother commented on her specific triggers:

I think for her, kind of every fall when I had to put her in the hospital. I kind of

hold my breath. Like that first anniversary of everything. I kind of held my breath.

Like this past school year, "The school year started. Is she doing okay? Is she

going downhill?" That fear, I have anxiety myself when she starts a new school

year.

Some parents interviewed described having pervasive unwanted memories that included unexpectedly remembering something, feeling as if the parent is going back in time, or unexplainable worry. These memories could best be described as intrusive

thoughts. One mother described an example of unexpectedly worrying about her daughter:

> *And maybe, just like, sometimes I just get these feelings like, "I need to go check on her now." Or when I'm driving home… it's just kind of that worry that, not that she's ever mentioned it except for once, but the self-harm.*

All parents interviewed articulated reflections on the past. Reflections included how caretaking used to be harder, considering treatment options, warning signs, feeling bad for their children, improvement over time, hindsight into their children's illnesses, talking to others in the past, blaming themselves, stories of challenges, conflicting emotions in the past, current confirmation of a past hunch, feeling unprepared, being in denial, coping with the diagnosis as a family, and reflecting on seeking help. One mother reflected on not initially understanding how severely her child suffering:

> *I think with [child's name] I didn't really… I didn't really understand how, how depressed she was and how anxious she was. And I, too, kind of wrote it off before I learned that she was hurting herself, like, "She's just being a teenager." But really it was way more than just being a teenager. And I think for all the sacrifice we make to send them to a private school, we kept them in kind of this little bubble where it's the same group of people, the same teachers, nothing changes… in a way I feel like I kind of failed them in how to cope with certain new situations.*

Parents were asked to comment on their subjective experience. Parents reported feeling invalidated, that their experience of having a child with mental illness is the worst experience of their life, guilt, shame, tired, exhausted, overwhelmed, helpless, challenged, frustrated, defeated, stronger, drained, limited, traumatized, alone, burdened,

shocked, hopeful, taken advantage of, relief when the child is not around, hypervigilant, and as if they lost control. Parents remarked on feeling as if they had learned a lot about themselves and their family in the process of coping with their children's mental illness and reported feelings gratitude and hope. One father commented on his subjective experience of adopting and being his son's caretaker:

And I don't want to resent [child's name] for anything because I know it's not him but there's times where I do feel so shitty about myself but I think how much different my life would've been if [child's name] would've been normal and healthy, then I would've never had to meet him, then I never would've had to go through any of this stuff. But then I feel ashamed because I'm so grateful for the [child's name] that I will always know. It's rough.

Another parent commented on her experience of raising a son with mental illness:

Raising him has been traumatic. Yeah, it's tough. It's tough. It's one of the toughest jobs I've ever had. I feel like I need my regular job to keep me with structure. He's so unpredictable and I just don't know, and I hate that not-knowing feeling.

All parents interviewed shared their thoughts on how the future looks for their children. Parents' thoughts of the future included uncertainty, making contingency plans, optimism, thoughts about future romantic partners, future employment, anxiety, possible death, concern about heredity of mental illness for children's children, hope, confidence, worry about treatment compliance, and having a sense of feeling bittersweet. One mother discussed her thoughts about her daughter's future:

Oh my God, it's so uncertain, I guess would be the word because, like I said,

some days she's just so on top of things and she's really doing a good job with

her current treatment, and other days she's just doing nonstop rituals and is very

unresponsive to me. And also just the way she treats me, I worry about her being

in a relationship with anybody because I think inevitably she might start trying to

transfer that over to them and start asking them to accommodate her or do things

for her, and I just think that person would be pretty likely to just bail because

they'd be like, "This is just way…" I know she can get a job. I'm wondering how

long she'd be able to keep it if things got bad for her. I obviously just want her to

be happy in whatever form that takes. She has been talking a lot about wanting to

be a therapist because I think she's really gravitating towards some of the kids

she has met with OCD who are not as well-off as she is and she really wants to

help them, and so I think having her go into some kind of helping profession

would be awesome because, like I said, she's really emotionally intelligent and I

think she could be really great in that field. So, I think something like that along

with a family. I know she really wants to get married and have kids and I think my

biggest thing is that she would learn to take care of herself.

In several interviews, parents discussed their expectations of how parenthood

would look, of how their child would perform and behave, of how custody and

guardianship agreements would look, and of making their children's lives different for

them. One mother discussed how her expectations of what parenthood would look like

have not been met: *You kind of feel like you've gone through all these steps and had kids*

and have a family and for what? You're not reaping any rewards. You're not having the

fun that you want to have.

Other parents interviewed discussed managing their lives by taking life one day at a time, remaining focused in the present, not spending time forecasting negative futures, doing what is doable, planning for what's next (e.g., college), and having confidence. One mother voiced this sentiment when discussing her current management of her grief:

So yeah, I think, "You know this is where we are and we're just going to take it day by day."

In several interviews, parents discussed the idea of moving on. Parents reported that both children and parents themselves engaged in attempts to move on by not dwelling on the past, focusing on family, creating boundaries, shifting perspectives, and accepting the past. One father discussed his process of moving forward:

But worst case scenario: something bad happens. We cry, we deal with emotion, we talk with who we need to talk to, we just keep on moving forward. Because once you stop moving forward then you're not really going anywhere. You know, you could be pushing back. I don't know. We're just moving forward, whatever happens.

Another parent discussed her daughter's attempt at moving on:

She's come so far, but you look at the scars on her arms and her legs and you know she's battled something in her past. She will tell you that it's kind of, for her, she looks at them and it's not a sad thing, it's not a bad thing, it's "I beat you." She just went to prom and had the tiny-strapped dress. And at first she was going to put makeup on her one arm. And she goes, "You know what? I don't

care." She goes, "They're healed. I'm healed. If someone has something bad to

say that's their problem, not mine." It kind of… It gives her a lot of strength.

Relationships

According to the parents interviewed, the relationships between their children and

others – friends, acquaintances, and family – were a prominent theme. These

relationships emerged as a general domain titled *Relationships.* This domain captured

how parents perceived their children's relationships with parents, siblings, extended

family, others in general, strangers, peers, and individuals in religious/spiritual contexts.

Overall, this domain captured how the children are perceived to interact and function

with others, and also the boundaries the child created in communicating their mental

health information to others. Core ideas included parent-child[2], child-peers[3], with others[3],

and child boundaries[3].

relationship: *And then she started really not liking me, very disgruntled with me, she*

didn't want to listen to me, she didn't want to be around me. Overall, she was just

unhappy with me as a mother. Other parents echoed the sentiment of having a fluctuating

relationship. One mother said: *Sometimes it just goes up and down. It's depending on… I*

try to be even keel but sometimes I don't know if she's going to be super loving or super

mad. Another mother captured this strain when she said:

> *It can be a strange relationship 'cause when you have children with strong*
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> *personalities they can be difficult to love. You always love them, but it's certainly*
>
> *a lot more challenging. I think he trusts us, but he's not a very nurturing kind of*

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[2] Typical

[3] Variant

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kid… It's not what I would call a normal parent-child relationship. I'm not saying it's a bad relationship; it's a different relationship, it's a tougher relationship. It's emotionally and physically draining, at times.

Another mother spoke to this relational strain reporting:

Right now it's good and bad. Like, her coping skills with her OCD a lot is avoiding things and so her dad and I, we try to push her a lot and she doesn't like it. She'd rather us just leave her alone to do her rituals and everything. But if we're not pushing her then she's fine.

This strain was echoed by another mother:

I'm a meal ticket, I guess. That's what I feel like. It's strained. I mean I love him and I'm trying but I get very frustrated and angry with him because he will not do what I want him to do.

A father also felt his relationship with his daughter was strained, stating: *Our relationship is… it's strained at times but I think that there's a solid foundation there.* Another mother discussed the variability of being close and then disconnected: *I feel like we are very close in some ways but then some ways she just likes to shut everyone out and so I'm just not really sure what she's going through, thinking, how she feels about things.* Other parents described their relationship with their child as "close" like one mother who said: *I would say we have a really, really close relationship…* Close relationships were sometimes characterized by open communication as described by one mother: *It's very close. She is a very good communicator so she talks a lot to both my husband and me.* And another mother who reported: *Really good. I'd say open. She*

always comes to me and tells me or if I notice that she's not having a good day then I'll just ask her and she'll tell me.

In several interviews, parents discussed the relationships of their children with same-aged peers. One mother mentioned her daughter's small social circle: *She's more geared toward having a best friend and having a lot of acquaintances at school, rather than she's never had a big gang on friends that she hangs out with.* A couple parents discussed their children's friend group with disdain for the peers, seeing them as bullies, dismissive, or enablers. One father said: *It seems to be that there are things that enable her to make it worse and I think that the communication that she has with her friend definitely enables this.*

Other parents discussed the relationships of their children with others. One mother discussed her child's interactions with family members: *She had this attitude with her grandparents, with me, with her brother, even her cousin who is pretty much like her sister.* Other parents remarked on how their child's mental health issues impacted their relationships with teachers, strangers, and relating to adults better than same-aged peers. One mother said: *She tends to be more comfortable with adults than with peers, which seems to be related to her mental health issues.*

Close to half of those interviewed discussed their children's boundaries of sharing their mental health with others along with how as parents they choose to respect and enforce their children's boundaries. Many reports revolved around children being private about their diagnosis, as one mother said:

> *The girls are extremely private about it, so besides my husband and my mom it's not public at all. And none of my family, her other grandparents, do not even*

know she was hospitalized. She is seriously protective of what she's been through.

Some of the parents discussed how they feel when sharing with others about their children's mental health issues and their comfortability often heavily relied on staying within the parameters of their child's comfort. One mother stated: *I think that it's a comfortable situation and I'm not just like sharing very personal information that [child's name] wouldn't want me sharing with people.*

Treatment Experiences

A prominent theme of treatment experiences was found among interviewees. This general domain titled *Treatment Experiences* captured the holistic experience of objective and subjective occurrences from pre-treatment to the current time. Parents discussed their experiences from deciding to seek help, to their interactions with providers in different settings, the challenges in the process, their efforts at embodying and implementing therapists' recommendations and homework, and their children's engagement in treatment. Core ideas in this domain included treatment experiences[1], parental enactment of treatment[2], treatment challenges[2], seeking treatment[2], and adolescent attitudes toward treatment[3].

Parents discussed their experiences with different treatment providers including social workers, psychologists, school counselors, pediatricians, and nurses. Children had been in outpatient therapy in clinics and schools, inpatient hospitalization, partial hospitalization, and a residential boarding school. Parental reactions to treatment

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[1] General

[2] Typical

[3] Variant

experiences ranged from pleased to mixed to dissatisfied. Some parents experienced the stress of unavailability of appointments and providers whereas others felt resources were plentiful and easily accessible. Positive experiences included feeling that therapy has been helpful as evidenced by a decrease in children's symptomatology, confidence in being able to communicate with providers, children being able to access providers independently, no waiting list, having a wide array of options for varying levels of treatment intensity, having access to a clinic with a good reputation, long-lasting therapeutic relationships, clinicians with expertise, flexibility of clinicians being on-call, having good insurance, observing the child in therapy and watching the clinician model interventions, having integrated care in a medical setting with behavioral health consultants, feeling prescribed medication is helpful, practical and helpful advice from practitioners, practitioners helping parents find in-network providers, and engaging in family therapy. Negative experiences included feeling as if the mental health provider pigeon-holed the child based on background information, providers not offering helpful tools or answers, medication used as a way to cover up but not correct symptoms, misinformation given to parents and children about treatment, long waiting lists for appointments, overly restrictive hospitals, seeing the child regress or not get better, feeling rushed in decision making, not being given informed consent or understanding parental rights, hospital discharges based on insurance timelines, adding another appointment or clinician to a schedule for a child who sees other providers for medical issues, the child exhibiting symptoms of another disorder after release from inpatient treatment, providers disagreeing about diagnoses and/or treatment options, misdiagnoses, lack of mental health resources, negative reactions to medication, therapists'

interventions escalating child's symptoms, looking for the right "fit" of a provider for the child, death of a provider during the course of treatment, and having medical practitioners normalize disordered behavior. One mother spoke to the positives and negatives of her experience:

> *It depends. The… She was in therapy when she was six and he was excellent. That went on for about a year. And then, when she first, when we first found out with the cutting stuff the therapist, the group that we were with, they were horrible. They did not… It was not about her. They were not concerned about her. They just wanted to know about me and they were more interested in talking to me than her and that wasn't what we were there for. Her current therapist is amazing. And the mental health people in the emergency room were fabulous. They were great. And then the ones as [hospital name], they were… I mean the staff there was tremendously helpful to her and our family. And I've talked with other people that have been in, well one other person, they were in another facility and she said it was total opposite, it was absolutely horrendous.*

Other parents interviewed talked about what they have learned and attempted to implement at home in terms of enacting treatment. One parent, as a mental health professional, incorporated modeling and reinforcing positive, prosocial behavior, and cultural values. Other parents took advice from professionals that included allowing the child a mental health day off of school or not discussing a family session for one hour after its commencement, creating discussion with their children about coping skills, implementing a rewards system at home, implementing specific strategies such as radical acceptance from Dialectical Behavior Therapy, using a balanced way of making

judgment calls and decisions, identifying triggers and openly and appropriately

discussing them with the child as they manifest, and completing homework assigned by

therapists. One of the adoptive parents discussed her experience of enacting treatment:

> *Way back then I think I really wanted some pointers from [psychologist's name].*
> *And he was trying to set an example that I could watch, how to deal with… so she*
> *wants to run off somewhere. Well, have her do something that you really want to*
> *do first. "We're going to clean up first before we go down the hall and make some*
> *copies" or whatever. It was something he could do and still stay in the office like,*
> *"Okay you do the 'if you do this then you can do this'" thing. So I'd start doing*
> *that at home and giving her stickers for rewards and it worked. She did like to*
> *comply, being compliant and getting the reward. So I was learning more how to*
> *deal with this situation.*

Other parents also discussed the challenges they faced with seeking and engaging

in treatment. Treatment challenges included feeling that having a child incarcerated might

be the best option for quicker mental health assessment, the gap in care due to lack of

integration between physical and mental health providers, an excessive waitlist or waiting

period for an appointment, a lack of one-on-one meetings with mental health providers,

feeling rushed and not retaining all information from providers, a lack of mental health

resources both locally and statewide, not collaborating with professionals or

understanding long-term goals/plans or length of stays in acute units, difficulty finding

providers who were available and accurate, unreturned phone calls, finding providers

who participate in insurance, having a therapist who lacks expertise, and advocating for

coverage from insurance companies. One boy's father spoke to his experience of treatment challenges:

> *I think there's definitely a sense of helplessness because you don't really know and availability of resources isn't great. A lot of times from the time we'd make the decision that we think he needs to go see somebody it'll be… it's like a couple months before you can get in and they want to meet the parents first and then it's like three months by the time you get your child an appointment. And just kind of feeling like you don't really know what to do as a parent.*

Some parents discussed their instincts and reactions for initially seeking help for their children. Parents who sought treatment initially sought help from the school/school counselor, a pediatrician, a social worker, a psychologist, psychiatrists, and advice from other parents for appropriate referrals. Parents also explained their preconceived notions that seeking help would help diagnose and address the problem to return their child to previous levels of higher functioning. Another finding was that the initial help seeking process was not a finite process, but was extended when parents discovered or providers recommended that the child utilize a treatment team (e.g., a therapist and a psychiatrist). One mother discussed the process of seeking help for her daughter:

> *…I went to my school counselor and talked with her and she got in touch with the middle school counselor and I immediately went over there and she'd already pulled [child's name] into the office and there were cuts on her arms at that time and so we immediately went to the pediatrician that day and so it's been over a year now that we've been going to the pediatrician and the therapist for that. It*

was… I saw it and within an hour-and-a-half I had her and I had her at the

pediatrician.

Other parents discussed their children's attitude toward treatment. Children's attitudes ranged from completely initiated by child to actively wanting to disengage services. This was also somewhat dependent on the particular treatment with which the child was engaging. Some children were so responsible for their counseling appointments that parents reported not being involved and having to trust the counselor is providing what the child needs and would contact the parent if necessary, whereas children who had been hospitalized were able to voice when they wanted to return home. Parents voiced relief at not feeling they had to force their children to engage in therapy appointments and their children's ability to ask for help. Parents perceived their children wanted to get well. Parents recollected when their children refused certain treatment options, such as medication, or when children felt placated by providers and were, therefore, oppositional. One mother spoke of her perception of her daughter being responsible for her treatment:

I think she's very responsible for it. She just got her driver's license last week and

it was, "I can make my own therapy appointments." And she only goes every two

or three weeks now. But like during finals, she went every week. She knows that

when she's nervous about something she needs to go more. She really is taking

responsibility for it on her own. And I think that's a good life skill to have. That

this something she has to manage. We just went for a medication check to the

psychiatrist and she said to her, "Do you think you want to taper off the

medication?" And [child's name] looked at her and she goes, "I'm not ready for

that." She really… And I was surprised because I thought she was going to say,

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"In a heartbeat. I don't want to take this medication." Because it has made her

gain a little bit of weight and that bothers her, but she's like, "No, I need it. I'm

not ready to try without it." So, I mean, I think she's in the right direction. That

it's something she needs to manage and she's going to have to manage.

Understanding

According to the parents interviewed, there were various dimensions of explaining, learning about, and making sense of their children's mental health diagnoses. Additionally, they spoke about learning and adapting to their new roles in parenting a child with mental illness. These ways of conceptualizing and explaining their children's diagnoses emerged as a typical domain titled *Understanding*. Core ideas in this domain included family history[2], roles of parents[2], understanding of diagnosis[2], pre-existing understanding[2], understanding prognosis[3], context[3], comparison[2], attribution[2], and lessons learned[2].

Over half of those interviewed considered a hereditary and/or environmental link to their child's mental illness by reflecting on the child's family history. Parents discussed children enacting behaviors similar to the child's family members (e.g., incarceration); the parent's own mental health issues; parents' family members with mental health diagnoses including siblings, parents, other children, and extended family; children with similar personalities as those within the family; and parents' perceiving their spouses or the child's other biological parent as having similar mental health issues as the child. One mother reflected on her process of connecting family history to her daughter's mental illness:

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[2] Typical

We did at various points in the process, my husband and I reflected on and I
ended up learning a lot about the anxiety in my family. Which I had known about
a younger sibling having a lot of issues with anxiety and panic attacks but she's
had a chronically ill child so that always seemed to make sense because it's what
she'd had to deal with… I knew that she had been on medication and had had a
lot of struggles with panic attacks and anxiety. But it wasn't until we'd been
working with [child's name]'s OCD for a while and I talked to all my siblings
about it then I realized all three of my biological siblings have anxiety, and I'm
pretty sure my older brother has OCD but doesn't really want to acknowledge
that it's at that level. He certainly has those tendencies but he feels like he has the
Os and Cs but not the Ds.

Interviewees also spoke about how they view their roles as parents. Parents normalized their worry for their children as worrying for their child is what any parent does, questioned their parenting skills and instilling doubt around feeling they were acting in their child's best interest, discussed shifting roles (e.g., becoming a legal guardian, staying in contact with biological parents), recalled assuming less responsibility for their child's mental illness and shifting the accountability to the child, reflected on adapting to the additional role of being an advocate, reported gaining insight into their role of contributing to their child's symptomatology, reported feeling a loss of parental control over the children when practitioners made treatment decisions (e.g., sending the child to inpatient), feeling a power shift in the parent-child relationship when unable to discipline or manage their child, become lay experts on mental health issues and treatment, and viewing the role of a support person as needing to be supportive at all

times. One father spoke of his acceptance of his role of not assuming all responsibility for his son's mental illness:

And I think it kind of helped to recognize that at the end of the day, and the approach his therapist has suggested to us, is just recognizing that our job is to support him and give him access to resources but at the end of the day he's the only one that can really help himself, and that we can't do it for him. And I think some ways it's part of parenting. As they get older, you can't do their school work for them, you can't pick their career for them, you can't… they have to… you have to give them resources and accessibility and support, but it's kind of up to them what they do with it.

Parents discussed their understanding, or lack thereof, of their children's diagnoses and symptomatology. Parents discussed their initial understanding and what they have learned, understanding it as an abstract concept and then as a lived manifestation, understanding current diagnoses as related to potential future diagnoses, understanding diagnoses intersectionality and comorbidity, understanding diagnoses as cyclical and lifelong, feeling as if they do not have a good understanding of their children's diagnoses and wanting more information, feeling as if their children's diagnoses are inaccurate based on their understanding of criteria do not align with symptomatology, gaining insight into how children's behaviors are enactments of mental illness, accepting children's behaviors as symptoms of mental illness, and having difficulty accepting the validity of their children's reported symptomatology and consequential diagnoses. One mother discussed her understanding of her daughter's mental health diagnoses:

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Her OCD, it's something that she has to constantly work at. If you don't work at it

it just gets worse and worse. And you can't just let it be around for a little bit

because if you don't deal with it it just gets worse and worse. And because of the

OCD then she got the depression because she couldn't do anything, and then later

on because of her perfectionism – is what our psychologist says – that's what led

to her eating disorder.

Many of those interviewed discussed their pre-existing understanding of mental

health issues and/or treatment options. These preconceived perceptions were based on

prior experience of having or knowing another child, family member, or friend/colleague

with a mental illness; attending school and professional trainings and/or currently having

career in the mental health or a related field; and having a spouse who was trained to

recognize mental health issues. One mother discussed her pre-existing understanding of

signs of mental illness and her ability to apply her knowledge to her daughter:

I was totally blindsided by it, I guess, one thing I was naïve about it. I had seen

signs and working in the school system we're trained to look for things like that,

and when it comes to your own kid I guess you don't want to see it, but she was

wearing the long sleeves all the time, like sweatshirts, hoodies, keeping her body

covered all the time when she was around me.

In addition to understanding their children's diagnoses, some parents discussed

their understanding of their children's prognosis. Parents had an understanding that their

children's mental health issues would be lifelong but had the potential of being managed

with appropriate treatment and engagement in treatment. Parents saw their children as

resilient, intelligent, and capable to manage their mental illnesses. Parents considered the

prognosis of their children's mental illnesses to include decision making for college and career choices, future romantic and peer relationships, and having to consider mental health as an important aspect of their lives. One mother discussed her perception of her daughter's prognosis:

> *I think it'll be a battle. I mean, she's going to have depression forever; it's not going to go away so I think it's just something she's going to have to cope with. She's going to have to learn some better coping mechanisms than what she currently has. I do know that she's brilliant, she's very, very smart, so hopefully she can take from all this experience and do something positive with it. That's what I hope.*

In several interviews, parents discussed their children's mental illness symptomatology manifesting more in one specific context. These reports included seeing worse symptoms in the home, in a large school setting (e.g., impairment in social functioning), violence with family members at home but not towards friends or peers at school, and in school and school-related tasks (e.g., perfectionism and decreased ability to complete schoolwork). One mother spoke of her daughter's illness as manifesting mainly in their home:

> *…but I don't think people would believe me if I said she had OCD because she has compartmentalized it in a way that it only comes out strongly when it's like she's at home, she doesn't have other obligations. So when she has to go to school, when she has got to go to work, when she's going to do something with her friends, she can contain it, and it all kind of comes out at home.*

Interviewees also discussed their thoughts of comparing both their children and themselves to others. Parents compared their children to their own upbringing, parents perceptions of other parents who are not raising a child with mental illness, compared their children's asymptomatic selves to their disordered selves, compared cultural norms around when it is acceptable to assume legal responsibility for a child, compared the struggles of being a legal guardian to being the biological parent of a child, comparing their treatment experiences including insurance coverage and wait lists to others, comparing their child to other children specifically around achieving developmental and social milestones, having different boundaries than parents of children without mental illness, comparing mental illness to physical and visible disabilities, comparing their reactions to those of a spouse, comparing children to siblings, comparing children to other patients in treatment, and comparing treatment of and education about mental illness to that of physical illness or injury. One mother discussed a comparison she made between her and other parents:

> *I remember going to one support group that said, "Yeah, you know what, if my*
> *kid won't eat their peas I make them sit at the table until they're gone." That's*
> *your issue, that they eat their peas?! Who cares! I'm just like, "Oh my god!" I*
> *don't know. What are the real issues in life here, you know? And they can come*
> *off looking like glowing parents. You have these kids who are such highly-*
> *motivated achievers and the parents really haven't had to do anything! And I*
> *think, "God, if they had a kid like mine, maybe they'd be better parents. Maybe*
> *they'd be more motivated. Maybe they'd talk." I mean… I remember this one*
> *situation where I watched a good friend of mine, she had three boys and they*

were playing a game and they were so supportive of each other, "Oh, that's okay,

you'll get it next time." And my boy's just like, "Dump the game. That wasn't

over." Things were just always chaotic in my house.

Other parents talked about the difficulty they had discerning their children's

behavior as disordered or typical teenage behavior. Parents were unsure of how to hold

their children responsible for behavior and how to navigate discipline and punishment.

Some parents who were initially in denial of their child's mental health diagnoses were

later able to attribute the child's behavior to mental illness after rationalizing it as typical

adjustment, some struggled with attribution due to gaining custody of the child during the

child's adolescent and not having a baseline of the child's behavior to which they could

compare current functioning, some struggled with attributing behavior to personality or

mental illness, some attributed their child's disordered to behavior to their parenting

skills, many could not differentiate their child's symptomatology from what they

perceived as typical teenage behavior, some discussed their providers' reluctance to

diagnose certain illnesses due to symptoms mimicking teenage behavior (e.g.,

differentiating bipolar disorder from hormone imbalances), some reflected on what may

have caused their child's mental health illness, and some worried about the possibility of

scapegoating the child for changes in family dynamics. One father spoke of his struggle

with understanding the cause of his son's behavior:

And I think the trickiest part we have now with him being 15 is how we've

definitely had instances where's it's like, "How much of it is his disorder and how

much of it is being 15?" As a parent it's hard because in terms of parenting and

when to discipline and how to discipline and so forth, it gets tricky. And you don't

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really want to punish him if it's his disorder but at the same time, you know, yeah,

there's challenges.

In several interviews, parents discussed how the lessons learned from their experiences added to understanding and management of their children's mental illnesses. Parents discussed how their parental identity had shifted, their paradigm and worldview had shifted to be more understanding of their child and other families, they view their experience as a learning experience to apply to their futures, and continually learning what types of interventions or ways of interacting with their children work or do not work. One mother reflected on an example of one of the many lessons she has learned from her experience of having a son with mental health issues: *So, you give him that mental health day and hope he's on track the next day and you learn what works, what doesn't work, and you keep your fingers crossed a lot.*

Supports

Based on the reports of parents interviewed, the support – or lack thereof – they receive for both their selves and their children was an integral part of their experiences. These different types of current and wanted support emerged as a general domain titled *Supports*. This domain captured parents' desire for more support (e.g., from schools, clinicians with particular expertise, support groups for themselves); the support they currently receive from schools, family and friends, and therapists; the support they get from taking care of themselves; advocating for their children and others in similar situations; and supporting other parents. Most parents indicated that support was necessary as they felt they had to become lay-experts in the area of their child's

diagnosis. Core ideas of this domain included current support[1], supports wanted[2], potential advice for other parents[2], empathy[2], school supports[3], self-help[3], self-care[3], advocacy[3], and supporting others[3].

Each parent interviewed spoke about the different types and intensities of support they currently have. Parents discussed varying types and degrees of support including religious community members and practices, family in general, friends, siblings, spouses, in-laws and parents, neighbors, online support groups, job environment and family-friendly policies, coworkers and colleagues, medical doctors, and therapists. Although each parent described support, they each had different struggles that accompanied their unique situation. One mother commented on the balance of asking for and receiving support while navigating challenges:

> *The thing is my sister said, "Don't tell Mom stuff. She'll worry too much." Like I said, she's a worrier, and they don't want her to die young worrying. She's 84 now so she's not that young. But I don't want to be the cause of her death with all my stuff. I just try to keep… not delve too deep with her. But I know she's a praying woman too so I'll just say, "I'm having a hard time dealing with [child's name] or whoever right now. Can you pray? And just think of me." I have good friends I talk to too.*

Over half of the interviewees discussed the types of supports they imagine would be beneficial. These supports wanted included having an advocate, more involvement in treatment, education and understanding of diagnoses, information about differing treatment options and requirements, and to feel heard by the child's providers. Of these,

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[1] General
[2] Typical
[3] Variant

many parents mentioned the need for a support group of some type, either informally like being able to sit down with another parent and chat over a cup of coffee or more formally with in-person support from groups of parents and possibly families with professionals present. One mother stated:

I think a support group would be excellent. Just having other people that have gone through the same things, that are willing to share experiences, advice, things like that, when the other people are there… maybe like a group session with other families where you could just meet, you know, once a month and just hash it out and get out your anger or your frustrations and just where you could talk with another human who has gone through the same things.

Interviewees discussed the advice they would give other parents who are in similar situations. Potential advice for other parents revolved around ideas of finding the right therapist and/or medical practitioner (e.g., expertise and fit) for the child, having strong support through groups or family, being able to listen to the child, having an advocate, researching as much as possible, thinking ahead and being prepared, voicing concerns and communicating with providers, engaging in self-care, and seeking help at the first sign of disorder. One mother voiced her advice to other parents, stating:

Oh, I'd say, "Make sure you get the right kind of therapist. One that really can understand know and give you the right support and direction. Don't stick with someone too long if they're not working out. Seek advocates. Don't let the school… Don't think that the school has your best interest in mind. You gotta surround yourself with support people."

Other parents also discussed their understanding of others' experiences. Participants empathized with other parents, their own children, other families, and other people in general. These interviewees empathized with their child's struggles, how other people may forget about their child's particular mental health struggles, how families with little or no support may struggle and feel loss, the difficulties that accompany being a teenager in today's Internet-frenzied world, how to use their experience as a child to relate better with their children, and why other parents may fail to go above and beyond for their children. One father reflected on how other families must feel, stating: *I can definitely understand where families with little support or in different situations can feel that loss. I mean, it could be huge.*

In several interviews, parents discussed the support they receive specifically from schools. This support ranged from individual teachers, principals, school and adjustment counselors, providers traveling to and working in schools, and 504 accommodations. When discussing her experience, one mother said:

> *When we moved here it was referred. She was crying in the lunchroom and the principal kind of brought her in and connected the two, but it was great. That person would come to the school and make appointments with [child's name] during the day so as opposed to me always leaving early and having to drive her somewhere. And then that kind of made it that confidentiality or like part of [child's name] to interact with this person. I think it was awesome. I think that's really helped with [child's name], like this is her person in her life that she can lean on.*

Of those interviewed, close to half of parents recalled their experience of engaging in different types of self-help. Self-help experiences included researching symptoms and diagnoses online, taking courses, reading books and articles, attending conferences, and completing workbooks with the child. One child's father reported:

We spent a lot of time learning about it from reading books, articles. We've gone to conferences. So we've definitely learned a lot about how they're interlinked and how people with OCD spectrum disorders are… depression is very common. Yeah, so I think from that standpoint we've learned quite a great deal.

Parents discussed their experience of attempting to care for themselves while balancing their responsibilities of parenting children with mental illnesses. Parents reported attempting to set boundaries, having a glass of wine at night, engaging in physical exercises such as going on walks, getting necessary sleep, healthy eating, stress reduction, putting their needs first, or sometimes lacking self-care and feeling exhausted and that they should be doing a better job. One mother summarized her management of stress:

If I'm stressed out about something, I go take a walk. I think I have my own coping skills for dealing with them: Go take a walk, go exercise, read, keep busy kind of things. Part of that too, part of my coping skills is touching… coming in contact with them, touching base with them. Are they okay? And I feel like the more information I have the better I can help them.

Interviewees reported their experiences of advocating for their children. Advocacy occurred and was defined in different ways including defending the child to professional mental health colleagues and friends, becoming an advocate through

research, actively fighting for the child's rights in treatment or in the school system, the child perceiving the parent as an advocate, and normalizing psychiatric medication as a treatment for mental illness to others. One father, a mental health professional, remarked on his experience:

And especially children and social, it made me more of an advocate for kids because I know now the firsthand struggle of how people write these kids off. Professionals write these kids off. And I know it's not right. so now I can use my position as a professional to try going the extra mile for these parents and kids.

Parents interviewed discussed their efforts to support others, specifically other parents in similar situations. Parents discussed how their experiences helped them directly support other parents in their own careers, giving other parents ideas, validating other parents and not judging them, getting involved in the community and raising awareness, encouraging parents to seek support, encouraging their family, giving direct advice when asked sharing providers' names and contact information, and donating books to the schools. One mother commented on her support of other parents:

I have the opportunity to be able to talk to a lot of people in what I do and I think a lot of people maybe feel like they've been to a therapy session. I'm willing to give that advice. I'm willing to share my experiences. And I'm willing to give them names and numbers and, "I don't know if they're taking people but these are some of the names that I've worked with. And yeah, I know that person and that person. In case that doesn't work out, don't worry about it. Keep going. Don't let it frustrate you. Take an advocate. They can be your voice. You're just

so caught up when you're in the schools and they're all talking and that's not

your area of expertise; let somebody help you."

Barriers

When discussing their experiences, all parents identified challenges. The vast

challenges these parents faced included confronting issues with their child, the mental

health and medical systems, and society at large. These different types of hurdles

emerged as a general domain titled *Barriers.* Core ideas of this domain included

finances[2], challenges to support[2], and stigma[2].

Every parent described experiencing financial challenges due to their child's

mental health, medical care, and consequences – such as legal – of their child's mental

illness, with the exception of one mother whose biological child is covered by Indian

Health Services. The financial impact was described on a continuum from "extreme" to

"no issues." Even those who described not feeling financial effects stated they had lost a

job or missed out on promotion opportunities due to needing to meet the caretaking needs

of their child and were aware of how money and time could be spent in other ways. One

mother captured this: *time and money could have been put toward different efforts*

instead of doctors' appointments and medications and that kind of stuff. One foster

father described that he went into severe debt attempting to cover his foster son's

physical and mental health needs. Other parents echoed this sentiment and included time

off work, gas money and time spent driving to and from appointments, and paying for

appointments. Parents voiced their concern with insurance, or relief if they found

insurance with better mental health coverage. Even parents who had insurance discussed

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[2] Typical

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having to pay out-of-pocket for different treatment options depending on if providers

participated in insurance and/or how much their specific insurance was willing to cover

for options covered in their plan. Several parents experienced legal consequences and had

related fines and legal expenses. A mother gave a comprehensive overview of her

struggle:

> *Monetary, finances, it's been quite expensive to have her in therapy. And then*
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> *with the hospital as far as gas, getting her back and forth, and the doctor's. I*
>
> *mean, we were, at one point, going to the pediatrician every week and therapy*
>
> *every week and those have been cut down now to the pediatrician, it's once, now I*
>
> *think we've every two months now, and therapy is once every two weeks but*
>
> *financially, I mean, it has been a burden. We have six children and it takes a lot of*
>
> *money to be able to support and do the things that we need to do for her.*

Other parents discussed the numerous challenges they faced in seeking support.

These varied from not having peers who could empathize or feeling awkward discussing

the situation with colleagues, feeling exhausted from explaining and re-explaining the

situation, the lack of support groups, the child's boundaries impeding on the parent

discussing the issues with others, a lack of awareness and understanding of mental health

disorders among others, feeling unsupported by treatment teams due to the focus on the

child, feeling as if therapists' advice is not practical or specific enough, not confiding in

others for fear of burdening them, fear of negative consequences of boundary setting, not

having community or school resources like a truancy officer, having the right teacher to

work with child, school standards reinforcing disordered behavior such as perfectionism,

fear of confiding due to soliciting unwanted advice, a lack of therapist expertise for

particular disorders, security breaches to and dismantling of online support groups, overburdened school systems and competing demands for educators and counselors, and the child having an invisible disability. One particular mother spoke to one of her struggles:

> *It's not cancer, it's not this, it's not that. But then on the other hand I'd say, "You know what, mental illness has this stigma to it that at times you almost wish it was cancer." Then, oh he could be treated and people would say, "Oh, that's too bad. Let's help you out. What can we do for you?" When it's mental illness, it's sometimes, "Oh, yeah, your kid could go wacky?"*

In several interviews, parents discussed their experiences of stigma, their fears of their children experiencing and suffering from stigma, their suspicions of stigma acting as a catalyst for their current social isolation, and their hopes to eventually break the stigma and normalize mental health issues as medical disorders. Parents reflected on their perceptions of others being judgmental, a lack of understanding leading to fear and misconceptions about mental illness, attributing social isolation to stigma from others, fear of disclosing to and confiding in others for fear of losing status or image, fearing their children becoming the subject of gossip and criticism, feeling embarrassed for others to hear their experiences, feeling as if their child's disorder was not taken seriously due to misrepresentation in media and entertainment, and witnessing their child be defined by others due to their diagnoses. Some interviewees discussed the intersectionality of factors such as race, sexual orientation, marital status, and/or parent-statues (e.g., biological versus foster) and how their experience of stigma was a

conglomerate of these identities and others' prejudices and discrimination. One foster

father spoke directly to this:

I guess just the stigma from mental health is a huge one because most of my

colleagues and friends are mental health professionals. And for me to see them

talk so despairingly with this mental illness, it made me sick and not really have a

high opinion of these professional anymore. And the opposite side of that is,

based on how I got custody of [child's name], I feel stigmatized for it but when I

talk to my non-Native friends and people I feel like I get judged for it, for

everything. And I think it's because they don't understand the Native way is when

it's one of our own who's hurt or needing help we take them in. It's what we do…

So I feel my own guilt and my own stigma against myself for what happened, but

it's also part of who I am. Just like the mental illness is a part of who [child's

name] is. And it's like we can't fully be accepted for anything. I would have to

identify [child's name] as my brother to most people. Because I felt that he's my

son and they'd say, "He's not your son." To me he was… It would hurt a lot when

I'd hear something like that. I was ashamed to have to identify him as my

brother… I only had two other experiences like this but for those people who

know my sexual orientation, there were people I can recall who would basically

blame how [child' name] acts on that… And it's like all this… the [child's name]

that I love and it's like of that version of him and it makes me just sad and sick to

think about people just writing him off as what his diagnosis is. And to see it all

reduced to an action and a diagnosis is sickening. Because he's never… in my

opinion if [child's name] were depressed or anxious, they wouldn't just say

that…is because they think about what this diagnosis means and then they jump

the gun and he's a criminal… I think there's a lot more stigma within Indian

Country about single dads.

CHAPTER IV

DISCUSSION

The initial intent of this investigation was to explore the experiences of parents of

adolescent children with severe and persistent mental illness, including their possible

experiences of grief, trauma, subjective burden, and objective burden. The two primary

research questions. Results indicated that these constructs were prominent themes of the

experiences amongst the current sample.

The majority of parents in this study endorsed the presence of grief, and several

acknowledged this grief was accompanied by loss and a great sadness or sorrow.

Notably, some parents denied experiencing a feeling of loss or grief. This could be

attributable to a variety of factors; however, there are no causal connections as to why

their experiences were different from other parents interviewed. A further inspection of

the transcripts of participants who denied experiencing grief revealed that two of the

parents interviewed were biological parents of the same child, and it is possible that

because their child was initially diagnosed about six months previous to their interviews

they are in a different phase of adjustment as compared to other parents. MacGregor

(1994) purported parental grief is characterized by three phases – avoidance,

confrontation, and reestablishment – with the avoidance occurring during the initial

months of diagnosis and includes sleeplessness and internal worry. It is possible that the

two parents who denied experiencing grief related to their daughter's mental illness are in

the avoidance phase of grief; they were not specifically asked about externalized

symptoms such as sleep and possibly have not externalized any unacknowledged or unnoticed internal worry that may be present. The other two parents who denied grieving their children's conditions were both recruited via online support groups and their children had never been hospitalized for mental illness related issues. Out of the sample, only one other parent was in an online support group whose child had also never been hospitalized and this parent endorsed the presence of grief. Meyers (2000) concluded the grieving process, both over the child and for oneself, may be easier for those who utilize support groups. Therefore, it may be probable that engaging in a support group intervenes and possibly serves as a protective factor for caretakers with children who have severe mental illnesses. In support of this, one of the two parents who was in a support group and whose child had never been hospitalized denied experiencing grief and elaborated that the amount of time (e.g., 15 years) had been an integral part of her getting "past it."

Parents reported experiencing loss pertaining to their child's mental illness. Although many parents reported experiencing this loss at the time of diagnosis, some parents illuminated they had felt a loss a significant time before their child received a diagnosis. Meyers (2000) asserted that the grieving process begins as soon as a loved one is diagnosed with a mental illness. However, findings from the current research point to some parents beginning this process long before diagnosis, although many reported feeling a significant loss at the time of diagnosis. This may be due to the high incidences of misdiagnoses, reports of long waiting lists when seeking an initial appointment, a lack of close and/or affordable resources from which parents could seek help, and attempting to use self-help resources to manage their children's undiagnosed mental illnesses. On the other hand, because grief is often an invisible and invalidated experience of parents

whose children have mental illness, some parents may themselves be unaware that what they are experiencing is grief or a loss reaction. Because grief reactions in parents may often be pathologized by mental health practitioners (MacGregor, 1994), parents may not have the language to describe and understand their experiences as grief.

A major finding of this research was the presence of grief among most parents of adolescent children with mental illness. Along with this, parents reported subjective burden and objective burden that seemed to be inversely related to social support. This extends past research that has found grief to be present among mothers and fathers of adult children with psychotic and mood disorders (Godress et al., 2005) and research that has found that social support, types of burden, and severity of mental illness were able to explain grief among family members of adults with mental illness (Solomon & Draine, 1996). The grief parents endorsed was described as cyclical and included internal and external losses, which is congruent with past research (MacGregor, 1994).

Parents described internal losses as decreased or obliterated confidence in parenting skills and loss of hopes and dreams for the future. These losses described by parents, both mothers and fathers, were congruent with past research findings (MacGregor, 1994; Ricard et al., 1999; Wiens & Daniluk, 2009) and can also be described as subjective burden (Provencher & Mueser, 1997). Past research identified six developmental types of subjective burden that were dependent and consistent with adult children's course of mental illness (Jungbauer et al., 2003). It is likely that this finding is consistent with that of the current research study: parents of adolescent children with more severe reported symptomatology are likely to perceive themselves as more strained and in need of more support as compared to parents whose adolescent children with less

symptomatology. A small number of participants denied experiencing loss, and one questioned the validity of his daughter's current diagnosis. Past research findings indicate that other parents, specifically one mother who had an adult daughter with schizophrenia, have denied feeling loss due to focusing on the physical presence of the child (Osborne & Coyle, 2002).

Parents described external losses such as loss of friends and social support, physical and mental health, finances and career opportunities, privacy, and a stable family system. These reported external losses are congruent with past research (Dore & Romans, 2001; MacGregor, 1994; Meyers, 2000) and can also be described as objective burden (Provencher & Mueser, 1997). Additionally, parents in the current study reported experiencing guilt, self-blame, and feeling responsible due to perceiving themselves as incompetent as well as responsible for mental illness being hereditary. Several parents in the current study endorsed feeling responsible for their child's mental illness but denied experiencing grief. However, it could be argued that these feelings define a grief experience but have not been validated as such by providers, family, friends, and society as a whole. Of particular importance, this research extends past findings that focused on parents of adult loved ones with bipolar disorder that experienced negative vocational, legal, social, and interpersonal consequences (Dore & Romans, 2001) and supports that caretakers of adolescents with other types of mental illnesses also experience these types of negative impacts.

A prominent finding of the extant research was parents reports of denial, anger, bargaining, depression, and acceptance experienced in cycles. This finding is supported by past research (Penzo & Harvey, 2008) in which Kubler-Ross's (1969) stages of

grieving were applied to parents of children with mental illness. Some parents described moving through all phases while some reported experiencing certain stages; regardless, all parents reported experiencing different emotions in cycles that were often triggered by children's psychiatric crises, major developmental or social milestones not being met, and unpleasant memories or triggering anniversaries. Because all parents endorsed experiencing a combination of these stages, it remains unclear as to if certain experiences of cycling through different stages should be categorized as grief reactions or trauma reactions. A reasonable explanation would be that a large majority of parents whose children have mental illness experience grief as described by Kubler-Ross (1969) in cycles, and others experience exacerbated grief reactions in combination with traumatic reactions (e.g., intrusive thoughts, hypervigilance, avoidance) as described by a small number of participants in the current research.

A core idea found in this study was the idea of majority of caretaking responsibility. This was a prominent theme of those who endorsed experiencing grief. Past research indicated that 80% of parents of adult children with schizophrenia and bipolar in one study experienced ongoing sorrow attributed to their limitless responsibilities (Eakes, 1995). The findings of the current study might help explain this finding: if parents of adolescents are found to feel the majority of caregiving falls solely on their shoulders, as was found to be true in this research project, while their children are adolescents, those who continue to serve as caretakers as their children age into adulthood will likely continue to feel their responsibilities are limitless and will, therefore, continue to experience sorrow. None of the parents in this study reported having children with bipolar or schizophrenia, though one reported bipolar was currently

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a rule out diagnosis. Additionally, two parents reported their child had a mood disorder with psychotic features and may experience greater, and limitless, responsibilities in the future.

Mothers, fathers, and legal guardians all described ongoing responsibility for providing care for their children. Past research that focused on mothers who were caretakers for their adult children diagnosed with schizophrenia described their experience as a lifetime of mothering (Ryan, 1993). Although the trajectory or lifespan experience for the parents in the current study cannot be defined, a similar finding of feeling constant responsibility for their maturing children was uncovered in all parents, not only mothers. The mothers in Ryan's (1993) study described disruption and loss, as defined by a disruption in their lives and relationships with their children and loss of their freedom and their children's potential for the future. They attempted to manage disruption by educating themselves and advocating for their children. Similarly, parents in the current study described disruption in their lives (e.g., socially, occupationally) and changes in their relationships with their children, loss of freedom (e.g., making social commitments, leaving the house) and loss of the children's potential for the future (e.g., graduating from high school), and attempting to manage disruption by educating themselves and advocating for their children. Therefore, it appears that mothers, fathers, and legal guardians of adolescent children with mental illness feel disruption and loss in their lives similarly to mothers who are caretakers for their adult children who are living with schizophrenia (Ryan, 1993).

Parents highlighted their children's personalities, initial onset of their children's mental illness, perceived changes in their children's behaviors and personalities, and

seeking help and treatment experiences. Additionally, they spoke of attempts at self-care, wavering views of the future for their children and their families, and emotions around the time of initial diagnosis. The themes of parents' reports are congruent with past research that focused on mothers of adult children with schizophrenia and schizoaffective disorder (Tuck et al., 1997). Parents descriptions of noticing children's initial symptoms, engaging in self-help and seeking treatment, persevering in helping their children, and having optimism for the future and a sense of moving on is congruent with past research findings of mothers of adult children with schizophrenia who identified four stages of their experiences: perceiving a problem, searching for solutions, enduring the situation, and surviving the experience (Howard, 1994). However, the current findings add to the research in that the current parent sample was comprised of fathers and legal guardians in addition to mothers and was racially diverse.

Like past research that was more longitudinal in nature that focused on married mothers' and fathers' experiences of children diagnosed with a major affective disorder or schizophrenia (Mohr & Regan-Kubinski, 2001), the current findings point to parents' seeking action, feeling overwhelmed, fearful, guilty, and having early nightmares for their child. However, parents in the current study described reliving and replaying memories of interactions with their child, including experiencing violence at the hands of their children, whereas past research highlighted bad dreams and intrusive memories surrounding their children's hospitalizations (Mohr & Kubinski, 2001).

Both mothers and fathers described distress and avoidance behaviors regardless of experiencing violence by their children, a finding that is congruent with past research that aimed to measure if these types of grief reactions were based on number of parental

contact hours with their child (Davis & Schultz, 1998). Therefore, the current study provides evidence that some parents are likely experiencing traumatic reactions and that grief as a construct should be deconstructed in order for these traumatic reactions to be validated, examined, and treated alongside and as a part of their total experience as opposed to as a symptom or characteristic of their grief experience. As opposed to using grief as an umbrella term to encapsulate traumatic reactions, the total experience of parents should be conceptualized as being comprised of grief and sometimes the separate but related construct of traumatic reactions. However, just as parents may not have the vocabulary to name their grief experiences, socially popularized language such as the term "trauma" may lend itself to be more known and accessible to parents. Therefore, it is important to further explore what parents mean when they use the terms "trauma" or "traumatic" in order to better understand if they are using those terms in a clinical or in a more common sense. While it is the goal to better understand parents' experiences, it is not the goal to pathologize parents who are are not experiencing clinically significant symptoms nor to water down the experiences of those who are. Because the current research utilized CQR which relies on phenomenology to understand experiences based on language, the results cannot be interpreted by the researcher but do support the notion that further exploration of parents' experiences and the language they use to describe those experiences is necessary.

Parents who denied experiencing loss at the time of diagnosis reflected on their experience as expecting to receive a diagnosis, engage in treatment, and see symptoms completely remit. However, when these expectations were not met, parents reported feeling sadness, grief, cheated, helplessness, hopelessness, and frustration. Parents spoke

of these feelings as being especially prominent when comparing their children to their same-aged peers without mental illness. These experiences have been described in past research focused on parents of adult children with schizophrenia and mothers of children with mental health and developmental disabilities (Ahmann, 2013; Ozgul, 2004). Additionally, the current research found this experience to be true for parents of non-adult children as well as for legal guardians.

Of the parents who endorsed experiencing grief in this study, one had a child who was diagnosed with a mental illness and had experienced a traumatic brain injury. This parent endorsed grief and a significant amount of anger toward herself, her son, and the mental health, education, and legal systems. Past research of parents whose adult children had schizophrenia and parents who had lost the essence of their children (e.g., personality) through traumatic brain injury indicated more ongoing grieving in the former and more substance abuse in the latter (Atkinson, 1994). This past finding supported the notion that parents' experiences may have differed based on their perception of the cause of their children's mental illness (Atkinson, 1994). While substance abuse in parents was not assessed in the current study, it was found that both parents of children with organic mental illness and the parent whose son had mental illness and a traumatic brain injury endorsed grief. However, it is plausible that a parent whose adolescent child has both mental illness and traumatic brain injury may experience more anger due to attributing responsibility both to biology as well as to the child.

The current sample of participants contained only one father whose son had transitioned to a residential boarding school where he stayed for a year-and-a-half before returning home. Past research indicated that of parents who served as caretakers of adult

children who were transitioning from home to a community residence, fathers reported significantly lower levels of depression, anxiety, emotional drain, and fear as compared to mothers (Cook, 1988). The current study did not quantifiably measure levels of depression, anxiety, fear, or emotional drain. However, grief was endorsed by the father whose son transitioned to and from a residential boarding school. Because his son had returned home, this father's experience cannot be compared to parents' whose adult children were living in a long-term care setting (Pejlert, 2001). However, one similarity in his experience as compared to past research (Pejlert, 2001) was the feeling of sadness he felt for his son, an attempt to accept hardships, and feeling bad for his son. Additionally, the current research supported past findings that parents who experienced violence by their children (e.g., punched by their children) experienced fear (Cook, 1988). Past research highlighted mothers of adult children with schizophrenia may possibly experience posttraumatic stress disorder based on their words used to describe their experiences (Howard, 1994). Although the current research did not objectively measure trauma reactions, parents of adolescents with mental illness described their experiences with similar words including "traumatic" and "devastating."

Close to half of the parents interviewed had experienced the involuntary hospitalization of their child. These parents reported feeling powerless, anxious, and negative interactions with mental health providers during this period. These findings are congruent with past research focused on mothers' experiences of the involuntary commitment of their adult children with schizophrenia (Crisanti, 2000). However, the current findings extend past results by supporting that both fathers and mothers

experienced anxiety, judgment, and negative interactions with mental health providers when their children were involuntarily hospitalized.

Past research has encouraged parents to be advocates and normalizers by attending community support groups (Meyers, 2000). Some parents in the current study reported that they learned more about others, such as colleagues, by sharing about their children's mental illnesses and felt empowered and connected when attempting to normalize and destigmatize mental illness by talking about it and through supporting other parents. However, many parents in the current sample were unable to find in-person support groups which led to further feelings of isolation. Parents in the current sample discussed giving advice to other parents, donating resources to schools, wanting to financially support other families, and wanting to collect and disseminate educational materials. These strategies can be seen as ways of making meaning from their experiences and are congruent with past research that highlighted how mothers of children with mental health and developmental disabilities made meaning of their experiences (Ahmann, 2013).

Interestingly, past research has indicated that increased burden and depressive symptoms were prominent among those who experienced grief and family stress while caretakers' pride in their relative with severe mental illness protected against burden but increased depressive symptoms (Chen & Lukens, 2011). Unlike past research, several parents – even those who endorsed feelings of grief and loss – expressed optimism for the future. This indicates that parents may find a silver lining in their children's mental illnesses, faith in the mental health system, and resiliency in their ability to provide care for their adolescents. It appeared that parents often focused on what their children were

capable of in the future, which is congruent with past research findings that parents may perceive certain losses as more fixable than others (Meyers, 2000). Parents in the current study who experienced grief also described negative family consequences, reactions including crying and exhaustion, and subjective burden; these experiences appear to be congruent with past research, though the quantifiable relationships are unknown and should be looked at in future research aimed at assessing both risk and protective factors in parents of adolescent children with mental illness.

The current research aimed to expand the small but burgeoning extant literature on the experiences of parents of non-adult children with severe mental illness. Results indicated experiences of noticing initial symptoms; a sense of loss; grief; isolation and lack of supports; managing multiple and often conflicting roles and responsibilities; and current, wanted, and barriers to support. These findings are congruent with past research that focused on parents of non-adult children with mental illness (Richardson et al., 2013). However, unlike past research, no participants had children with known comorbid developmental disabilities. Also, the current project included participants who were biological mothers, biological fathers, one custodial grandmother, and one legal guardian with a larger age range (25 to 60 years). And unlike past research, the current project focused on experiences of parenting a teenager aged 13 to 18 years old, rather than looking at experiences of both children and adolescents (Richardson et al., 2013). This diverse sample was found to have experiences similar to those of past research. Additionally, the current research extends the extant by extending understanding the experiences of parents of adolescents who have major depressive disorder, major depressive disorder with mood congruent psychotic features, posttraumatic stress

disorder, conduct disorder, and attention-deficit/hyperactivity disorder who had been

diagnosed anywhere from six months to 10 years before the time of their parents'

interviews. Lastly, the current sample indicated whether their children had ever been

involuntarily hospitalized ($n = 7$); therefore, results may be more generalizable to parents

of teenagers with severe mental illness.

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

This qualitative study was meant to provide an exploration of parents'

experiences of having children with severe and persistent mental illness. Although

participants included fathers, mothers, and legal guardians discussing their children who

had been diagnosed with anxiety, mood, eating, and/or impulse-control and conduct

disorders, caution should be applied when understanding and generalizing these results to

all parents who have children with mental illnesses. Participants were conveniently

sampled from online support groups, an organizational newsletter, and via word-of-

mouth. Additionally, participation requirements included the parents' children to

currently be in treatment. Therefore, it is likely that these participants are not

representative of all parents whose children have severe and persistent mental illness. Not

only were parents' children receiving some type of mental health treatment, but many

parents were receiving support themselves (e.g., in an online support group). It is likely

that parents who engage their children in treatment and receive their own support are

more likely to have been exposed to the recruitment advertisement and also to engage in

the process of seeking to speak about their experiences for the purposes of this research.

Parents whose children are not in treatment and who do not receive support themselves a)

did not qualify to participate in this research project, and b) may be more overwhelmed

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and less equipped to engage in an extra task such as taking the time and energy to speak of their experiences.

It is imperative to highlight that while qualitative research lends itself to the phenomenological understanding of participants' lived experience, researcher bias is an inherent threat. Although the research team made stringent efforts to eliminate bias from interviews and data analysis, caution should be applied when attempting to explain and generalize these findings. Additionally, parents' own mental health issues were not assessed and could determine their baseline and tolerance for stress, managing their children's mental health symptoms, and overall level of stress and burden.

While the current project was comprised of a racially diverse sample, more fathers and custodial caregivers are needed as participants in future research. Many participants also mentioned the necessity of researching the impacts on the siblings of adolescents who have mental illness. It would likely also be beneficial to start a longitudinal qualitative research project to measure if and how parents' experiences change overtime as both they and their children age.

Implications

The current research findings point to many important implications. Mental health professionals need to provide education to parents about diagnoses and treatment. This would include providing an accurate diagnosis, explaining the criteria and rationale for diagnosis, educating parents about the empirically-supported treatments for the disorder, and an expected prognosis. Additionally, mental health professionals should educate parents about possible pre- and post-crisis procedures, including limits of confidentiality,

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mandated reporting, when hospitalization is unavoidable, and what the process would look like in the event of an involuntary hospitalization.

This sets the stage for mental health professionals to include parents in treatment planning, decision making, and check-in sessions with the provider. Mental health professionals should provide parents with on-call resources that are available after hours and on the weekends both for their personal support and in the event of a crisis. Mental health professionals could strengthen the support for parents and their children by making referrals for the parent to engage in individual therapy, couple's therapy, and possibly family therapy, preferably within the same agency as the child's therapist. Another way to increase support and communication would be to have parents sign releases of information for the child's medical provider, school counselor, and other important family members in the early sessions of treatment.

Another important task that should occur early but should also be ongoing is the normalization of the parent's feelings and reactions; mental health professionals should engage empathically with parents and help provide information about normal reactions, including that reactions – which may include sadness and sometimes grief – often occur in cycles but that support is always available. Importantly, treatment options (e.g., medication, hospitalization) should be normalized and de-stigmatized by providing accurate information and similar physical health analogies (e.g., treatment of asthma).

Next, mental health professionals could work as advocates by creating support groups in their organizations for parents or by providing information to parents about community or on-line support groups, as well as regional, national, and international organizations and conferences that are in existence. A major need is for mental health

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practitioners to continue to, or re-engage in, participating in insurance networks. Additionally, mental health providers should continue to train and develop expertise in treating specific disorders. When providers are not able to provide empirically-supported treatment, they should refer to a competent colleague; this may include the use of telemed technologies.

On a larger scale, mental health professionals should continue to work as advocates in their organizations and at the state or federal levels to revamp or create policies surrounding discharge planning from acute settings, the number of accessible treatment centers and organizations, and budgets allotted for mental health. This advocacy can be fueled by further research and should include organizational outcome studies, research that utilizes a quantitative methodology to measure parents' experiences, and research that further illuminates the experiences of parents of non-adult children with mental illness who have children who are 12 years old and younger. A beneficial addition to research in the future would include using a mixed-methodology to understand the phenomenological experience of parents while also being able to quantify and compare relationships of constructs inherent in their experience. Future research should also attempt to compare groups of parents of adolescents with severe mental illness, either by type of mental illness or to parents of adolescents who have experienced other types of loss (e.g., death of an adolescent).

Conclusion

The findings of this research indicate that parents of adolescent children with severe and persistent mental illness experience grief, trauma, subjective burden, and objective burden. The main findings indicate seven domains that encapsulate these

parents' experiences: relationships; supports; barriers; evolving behaviors, feelings, and attitudes; treatment experiences; impacts; and understanding. It is notable that parents reported both positive and negative experiences pertaining to their relationships with their children, interactions with mental health providers, sources of support, and with lessons learned. Parents were able to withstand and survive seemingly-contrary emotions of hopelessness and hope, hate and love, exhaustion and perseverance, disgust and delight, helplessness and resiliency, fear and courage, anxiety and acceptance, grief and joy, and loss and gains. It is imperative that further, more-inclusive research be conducted with parents of adolescents who have mental illness in order to better treat adolescent clients by way of including, understanding, and treating the family system.

APPENDICES

ADVERTISEMENT/EMAIL FOR RECRUITMENT

Hello!

My name is Lindsay Yates and I am a Counseling Psychology doctoral candidate in the Counseling Psychology and Community Services department at the University of North Dakota. I am doing research on the experience of parents of adolescent children diagnosed with severe and persistent mental illness under the supervision of Doctor Cindy Juntunen.

I am specifically recruiting English-speaking custodial parents (18 years of age or older) of an adolescent (aged 13 to 17 years old) diagnosed with a severe and persistent mental illness, of any gender and ethnic background to participate in an interview that will take approximately **60 minutes**. Individuals are also invited to participate in an in-person interview about their experiences. Phone and Skype interviews may be set up instead of in-person interviews if this relieves any additional stress for participants. This research has been approved by the Institutional Review Board at the University of North Dakota.

For the purposes of this research, severe and persistent mental illness is defined as any diagnosis in the following categories, as defined and outlined in the *Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-V;* APA, 2013):

> -Schizophrenia Spectrum and Other Psychotic Disorders
> -Bipolar and Related Disorders
> -Depressive Disorders
> -Anxiety Disorders
> -Obsessive-Compulsive and Related Disorders
> -Trauma- and Stress-Related Disorders
> -Dissociative Disorders
> -Somatic Symptom and Related Disorders
> -Feeding and Eating Disorders
> -Disruptive, Impulse-Control, and Conduct Disorders.

-Your child must have **<u>one</u>** diagnosis that fits into one of the above categories.
-Your child must have been diagnosed **at least <u>6 months ago</u>**.
-Your child must have been **diagnosed by a <u>medical or mental health provider</u>** (e.g., general practitioner, psychologist, psychiatrist, social worker, counselor, nurse practitioner, physician's assistant, or other related providers).
-Your child must currently be receiving mental health services.

Those interested in participating should email the principal investigator (Lindsay.Yates@und.edu) and provide your phone number. The principal investigator will contact you, after ensuring you meet participation requirements, to set up a convenient date and time to complete an interview. You are not obligated to participate in this research and if you do choose to participate, you may terminate your participation at any time without consequence.

Please email me if you are interested in participating: Lindsay.yates@und.edu

Thank you so much! P.S. Feel free to forward the link to others who might be interested!

Lindsay Yates, M.S.
Dept.: Counseling Psychology and Community Services
Position: Doctoral Student
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Cindy Juntunen, Ph.D.
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THE UNIVERSITY OF NORTH DAKOTA
CONSENT TO PARTICIPATE IN RESEARCH

"Parents of Adolescent Children with Mental Illness: A Qualitative Exploration of the Lived Experience

PROJECT DIRECTOR: Lindsay Yates, M.S.

        701-777-3740 (Project supervisor: Cindy Juntunen, Ph.D.)

DEPARTMENT: Counseling Psychology and Community Services

STATEMENT OF RESEARCH

A person who is to participate in the research must give his or her informed consent to such participation. This consent must be based on an understanding of the nature and risks of the research. This document provides information that is important for this understanding. Research projects include only subjects who choose to take part. Please take your time in making your decision as to whether to participate. If you have questions at any time, please ask.

WHAT IS THE PURPOSE OF THIS STUDY?

You are invited to be in a research study about your experiences as a parent of an adolescent (age 13 – 17 years old) who has a severe mental illness. The current exploratory study aims to investigate the experience of parental loss and grief in parents of adolescent children with severe and persistent mental illness. The aim is to better understand these parents' experiences by conducting qualitative research in which parents can express their experiences of having children who have been diagnosed and treated for severe mental illness.

HOW MANY PEOPLE WILL PARTICIPATE?

At most, 15 people will take part in this study at the University of North Dakota.

Date: _____
Subject Initials:_____

HOW LONG WILL I BE IN THIS STUDY?

Your participation in the study will last about one hour.

WHAT WILL HAPPEN DURING THIS STUDY?

Should you choose to participate, you will engage in one interview. You and I will schedule a time that works for you. You will be interviewed in person, on UND's campus, or via skype or phone if you are unable to schedule an in-person meeting. The interview will consist of semi-structured, open-ended questions to allow you to describe your experiences as a parent of a teen who has a mental illness. Each interview is expected to last approximately an hour. The interview will be audio recorded, but no identifying information will be attached to the audio recordings. Any names mentioned in the audio recorded will be de-identified prior to data analysis.

WHAT ARE THE RISKS OF THE STUDY?

The anticipated risk is minimal. However, you might experience some emotional or psychological discomfort when talking about your experiences. There are no anticipated physical or financial risks. Additionally, if you experience discomfort or distress, contact information for counseling and health services through the UND Counseling Center and Northern Lights Behavioral Health Clinic will be provided to you.

WHAT ARE THE BENEFITS OF THIS STUDY?

You may not benefit personally from being in this study, but you may gain additional insight and understanding to your own knowledge, awareness, and skills related to parenting a teen with severe and persistent mental illness. However, we hope that, in the future, other people might benefit from this study because better undertanding parental experiences of those who have a child with severe mental illness can contribute to educating psychiatric and medical providers on how to better serve the families with whom they work. By gaining this understanding, practitoners can improve their services to provide more holistic, family-focused interventions. By focusing on the family as a system, including the parents in treatment, and understanding the interactions of parental symptoms on child functioning, treatment of children with mental illness should yield more positive results.

ALTERNATIVES TO PARTICIPATING IN THIS STUDY

An alternative to participating in this study is to choose to not participate. You also have the right to end participation at any time without any negative consequences. Specifically, your desire to not participate in the study or end participation at ANY time throughout the interview will not result in negative consequences or loss.

WILL IT COST ME ANYTHING TO BE IN THIS STUDY?

You will not incur any costs for participating in this research study.

WILL I BE PAID FOR PARTICIPATING?

You will not be provided payment for participating.

WHO IS FUNDING THE STUDY?

This project and the primary investigator are not receiving funding from other agencies, organizations, or companies to conduct this research study.

CONFIDENTIALITY

The records of this study will be kept private to the extent permitted by law. In any report about this study that might be published, you will not be identified. Data obtained in the interviews may be reviewed by Government agencies, the University of North Dakota Research Development and Compliance office, and the University of North Dakota Institutional Review Board.

Any information that is obtained in this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. If I write a report or article about this study, I will describe the study results in a summarized manner so that you cannot be identified.

The interview will be audiotaped for future analyses. Only the principal investigator, associated research team members, and people who audit IRB procedures will have access to the data. Confidentiality will be maintained by keeping all identifying information separate from the responses you provide and not discussing your participation in the study or information you provide outside of the interview process. Your demographic data, audio files, and transcriptions of the audio files will be electronically encrypted on the primary researcher's computer, all in separate files. All sources of data and consent forms will be kept for a minimum of three years, and destroyed after no longer than seven years. Consent forms will be destroyed through shredding. Electronic data and information, including your demographic data, the audio files, and transcriptions of these audio files will be permanently deleted from the primary researcher's computer.

IS THIS STUDY VOLUNTARY?

Your participation is voluntary. You may choose not to participate or you may discontinue your participation at any time without penalty or loss of benefits to which you are otherwise entitled. Your decision whether or not to participate will not affect your current or future relations with the University of North Dakota

CONTACTS AND QUESTIONS?

The researchers conducting this study are Lindsay Yates, M.S. (principal investigator) and Cindy Juntunen, Ph.D. (dissertation chair and student advisor). You may ask any questions you have now. If you later have questions, concerns, or complaints about the research please contact Lindsay Yates, M.S. at Lindsay.yates@und.edu or Cindy Juntunen, Ph.D. at 701-777-3740 or cindy.juntunen@und.edu.

Date: _____
Subject Initials:_____

If you have questions regarding your rights as a research subject, you may contact The University of North Dakota Institutional Review Board at **(701) 777-4279**.

- You may also call this number about any problems, complaints, or concerns you have about this research study.
- You may also call this number if you cannot reach research staff, or you wish to talk with someone who is independent of the research team.
- General information about being a research subject can be found by clicking "Information for Research Participants" on the web site:

http://und.edu/research/resources/human-subjects/research-participants.cfm

I give consent to be audiotaped during this study.

Please initial: ____ **Yes**   ____ **No**

I give consent for my quotes to be used in the research; however I <u>will not</u> be identified.

Please initial: ____ **Yes**   ____ **No**

Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Subjects Name: _____

_____   _____
Signature of Subject   Date

I have discussed the above points with the subject or, where appropriate, with the subject's legally authorized representative.

_____   _____
Signature of Person Who Obtained Consent   Date

SEMI-STRUCTURED INTERVIEW

Demographics

Relation: _____   Age: _____   Race: _____

Teen's sex: _____   Teen's age: _____   Teen's Dx: _____

Date of Dx: _____   Practitioner who Dx: _____

How long in treatment: _____   currently in Tx: _____   Hospitalizations: _____

1. I'd really like to learn more about (young person's name).
   Can you describe (young person's name) personality?
   What does (young person's name) mean to you?
   What is your relationship like with (young person's name)?
2. How did you come to learn that (young person's name) has a mental health condition?
   Are you able to talk through what happened?
3. Some parents have said that, before taking their child to see a psychologist or another health worker, there was a period of time where they felt like something just wasn't right with their child. Perhaps it was the way their child behaved, or how their child got on at home or school, that first indicated that something may be going on. How about you, what was your experience like?
4. When you first suspected that (young person's name) may have a mental illness, can you recall how you felt?
   What kind of emotions did you experience at the time?
   What was that like for you?
   Can you tell me more about those feelings?
5. During that time, what kinds of things were running through your mind?
   What went through your head back then?
   Do you recall thinking about certain things?
6. When you were first told by a health professional (such as a psychologist or GP or social worker or psychiatrist) that (young person's name) has a mental health condition, what was that like for you?
   Are you able to share with me some of those feelings?
   Can you describe the emotions you felt?
   What went through your head at the time?
7. Some parents have said that when they were first told their child had a mental illness, they felt a sense of loss. Did you experience anything similar to this, when you first found about your child had a mental health condition?
8. Some moms and dads have said this loss was associated with great sadness or sorrow. Did you experience a similar feeling, or was your experience different, and how?
9. Has (young person's name) received a specific mental illness diagnosis?
   [If YES]
   What is your understanding of this diagnosis?
   What does this diagnosis mean to you?
   How did learning of this diagnosis make you feel?
   Can you recall how you first reacted, when you were told (young person's name) has this illness?

10. When you first found out about (young person's name)'s mental health condition, how did you cope with those strong feelings and thoughts?
    How did you go on?
    How did you manage?
11. How do you currently feel about (young person's name)'s mental illness?
    How are things for you now?
    How do you feel, talking to me about (his/her) condition?
    Can you describe some of the feelings you have when thinking about your child?
12. Some parents describe a sadness in them, when talking or thinking about their child. I'm wondering if you've ever felt this way? Or is your experience different?
13. Would you say that you're grieving your child's condition?
    [If YES]
    What is that like for you?
    Can you tell me about that?
14. Have there been times when you've felt angry, or worried, or resentful, sad, or perhaps frustrated, when thinking about (young person's name)?
    [If YES]
    What is that like for you?
15. Are there certain things—such as events, memories, or perhaps certain times of the year—that bring up these feelings you have?
    [If YES]
    What sorts of things bring up those feelings?
16. Do you ever find yourself thinking back to the time when you first found out about (young person's name)'s mental health issues?
    [If YES]
    What do you think about?
    How does it make you feel?
17. How do you see (young person's name)'s future?
    What kind of hopes or dreams do you have for (young person's name)?
    Have these hopes and dreams changed since he/she developed this condition?
18. How do you feel when thinking about his/her future?
19. What does (young person's name)'s mental health condition mean to you?
    What does his/her condition mean for your hopes and dreams?
    What about the hopes and dreams of your family?
20. In what ways has (young person's name)'s mental health condition affected your life?
21. As a parent of a young person with mental health issues, how do you cope or manage?
    How have you been getting on lately?
    Are there things you do to feel better or cope with strong emotions?
22. Are there people in your life you can turn to?
    Can you talk about your experiences with someone?
23. How do you feel about talking to others (family, friends, relatives, neighbors, colleagues, health professionals, for example) about (young person's) mental health condition?
    Are there obstacles that stop you from, or make you feel hesitant about, talking to others about your experiences?
24. What, if any, have been some challenges for you, as a parent of a young person with a mental health condition?
25. Would you say that (young person's name)'s mental health condition has impacted on your family's day to day life?
26. Have you ever witnessed (young person's name) be violent to him/herself or others?
    Have you ever been threatened or experienced physical violence by (young person's name)?
    How did you feel in that moment?
    How did you cope?
    How has that affected your perception of (young person's name)? Your relationship?
    Do you relive those moments, or have nightmares of those moments?
27. What objectives negative consequences have you experienced, such as health? Finances? Social support? Legal consequences?

28. Overall what is your subjective experience? How do you feel about your experience and situation?
29. If you were to offer advice to parents in a similar situation to you, what might you tell them?
30. How would you describe your experiences with the mental health services you've accessed regarding (young person's name)'s mental illness?
31. Finally, if support was available for parents who were having some difficulty coping with, or adjusting to, their child mental health issues, what kind of support do you think would be helpful? By ''support'', I mean things like counseling or therapy.
    What do you think parents need in this situation?
32. Thank you again for sharing your experiences with me, your comments have been very helpful. That covers the things I wanted to ask you today. Is there anything you would like to add? Any comments you'd like to make? Thanks very much, I really appreciate your time.

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