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Grief and lost potential in the parents of adult children with severe mental illness.

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GRIEF AND LOST POTENTIAL IN THE PARENTS OF ADULT CHILDREN WITH
SEVERE MENTAL ILLNESS

By

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B.A., University of Louisville, 2005
M.A., University of Louisville, 2007

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Department of Psychological and Brain Sciences
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ABSTRACT

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Karen Eisenmenger

July 02, 2012

This dissertation is an investigation into the intensity, nature, predictors, and time course of grief that parents of adult children with a severe mental illness experience. This is an area of research that has not been fully understood or addressed by the mental health community. Parents were recruited through National Alliance on Mental Illness (NAMI-KY) family support group meetings. Each participant completed a package of anonymous surveys measuring grief due to the mental illness of their child, parental burden, and vocational lost potential, as well as completing demographic information. The results of the statistical analyses indicated that parental grief begins after receiving a diagnosis, and then decreases sharply after about six years. In addition, the child's current age was found to significantly correlate with grief intensity in the parent; the negative relationship suggested that grief is higher the younger the child. These findings indicate that early intervention with the parents could be helpful in processing grief, which in turn would likely assist the adult children with managing their illness.

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INTRODUCTION

The death of a child is typically considered the most painful grief for anyone to bear (Burnett et al., 1997). While most people accept the notion that parents who lose children to death suffer from grief reactions, it is not as likely that grief reactions to an adult child's severe mental illness would be anticipated (MacGregor, 1994). It has been demonstrated, however, that these parents also experience the loss of a child, since the adult child they have known, loved, and raised has been "replaced" with a stranger exhibiting the symptoms of a severe mental illness (SMI), such as schizophrenia. This occurs because the symptoms of a severe mental illness can drastically change the personality and behavior of the affected child and, as a consequence, the relationship between the parents and the child (Godress et al., 2005).

A case study of a parent with a child suffering from schizophrenia illustrates this change in a real world context (Osborne & Coyle, 2002). The authors interviewed a parent who described how her son changed from a laid-back, easy going young man to one who got into fights and berated her. The mother described feeling as if she had lost her son to a 'living death,' as his relationship with his parents 'broke down'. She watched his academic ability decline, along with her hopes and dreams for her son's future happiness and aspirations. She said that she sometimes experienced that her son's former self was trapped, since he would occasionally laugh and act like he did before his illness. This gave her hope that her son would return one day. Until his diagnosis, she experienced that he was becoming verbally abusive, alienated, and very stubborn,

ignoring others' point of view. The mother went on to say that it was 'earth shattering' when her son was diagnosed with schizophrenia and that she and her husband experienced tremendous guilt for causing stress in his life.

The impact of the mental illness on the family

With deinstitutionalization, parents became the unprepared, unsupported primary caregivers of many adult children suffering from severe mental illness (Cook, Lefley, Pickett, & Cohler, 1994; Mendenhall & Mount, 2011). A survey conducted with 203 family members of individuals with a severe mental illness demonstrated the frustration families have had to endure (Holden & Lewine, 1982). Most of those surveyed had a family member with schizophrenia (71%). They were mailed a questionnaire regarding the impact of their interactions with the mental health providers they encountered. Many family members found that these interactions caused them to feel guilty, confused, ignored, defensive and uninformed. A third of the family members (33%) said the interactions were not helpful, causing frustration (38%) and feelings of powerlessness (13%). Unfortunately, for over half of the families (53%), mental health providers were the primary resource for assistance. Interactions such as these may make it difficult for family members to address any grief they may be feeling with mental health providers, who may not appear to care about them. Mental health providers need to become more aware of the therapy needs of these parents and to communicate more sensitively and effectively with this population. Some mental health professionals have even openly accused parents of causing the child's disorder through inadequate parenting and negative intentions (Lewine, 1979; Holden & Lewine, 1982).

The family members also reported that living with someone with schizophrenia was like 'tiptoeing through a minefield' (Holden & Lewine, 1982). Many (77%) reported the tension and feelings of helplessness never end and are difficult to bear, straining family relationships. The tension was believed to have caused medical problems in 47% of the family members. Financial strain to some degree was endorsed by 74% of the family members, with serious financial issues affecting 32%. The symptoms of schizophrenia that caused the most problems for the family members were: aggression (24%), irrational beliefs (24%), unpredictability (16%), social inappropriateness (13%), withdrawal (9%), poor hygiene (7%), talking to self (3%), not assisting with chores (1%), and others (3%). This study was particularly enlightening with regard to the day-to-day situations families of those with schizophrenia experience. These problems do not describe the grief that family members suffer, but do illustrate the range of issues that parents of children with SMI have to endure. These problems will be differentiated in a later section from the actual grief that the parents suffer in response to the loss of the adult child.

Aside from dealing with the difficult symptoms of schizophrenia, there is also a great deal of heterogeneity of symptoms, making it difficult for family members to anticipate what a diagnosis of schizophrenia really means for their loved one (Lewine et al., 1982). While the frequency of each symptom is relatively stable across populations with schizophrenia, the symptoms that occur within any one person with schizophrenia are heterogeneous; there are no clusters that typically occur within patients (Lewine et al., 1982). This inability to predict symptom presentation may increase the level of stress for family members. They may interpret changes related to illness symptoms as willful

actions on the part of the ill person, who simply appears to no longer be considerate or loving toward them. Those with schizophrenia, however, may be unable to understand how others feel, think or react, which can interfere with their ability to have successful interpersonal relationships. They may not understand how their isolation or unusual behavior may be negatively interpreted by friends and family members. When those with schizophrenia begin to isolate themselves due to hallucinations, delusions, or depression, family members may feel their loved one is gone and has been replaced by a reclusive stranger. The family members may feel unloved, unnecessary, and unappreciated by someone who used to be loving and interactive.

A particular difficulty that the families of individuals with schizophrenia have to contend with is the increased risk of suicidal behavior. The suicide rate in individuals with schizophrenia is higher than in bipolar disorder or depression. Of those with schizophrenia, 6-15% will die from suicide and up to 50% will attempt suicide at least once (Lewine, 2004).

Parental grief due to the severe mental illness of a child

Grief due to the natural death of a loved one has been conceptualized as progressing through stages (Bowlby, 1961; Kubler-Ross, 1969), although this was not empirically tested for many years (Maciejewski et al., 2007). A longitudinal cohort study of grief (Yale Bereavement Study) was utilized to test the following stages of grief: disbelief, yearning, anger, and acceptance (Maciejewski et al., 2007). The authors found that grief due to the natural death of a loved one primarily involves acceptance and yearning. All of the indicators, however, reportedly peaked in the sequence proposed by the stage theory of grief.

The diagnosis of schizophrenia in a child has been linked to parental grief (Godress et al., 2005). It has been suggested that this grief has been overlooked by those providing treatment to the adult children (MacGregor, 1994). There appear to be no prevalence statistics to document how often this occurs, however.

With so much change in caring for the mentally ill occurring in recent decades, the grief these parents may experience has not been addressed thoroughly (Miller, 1996). The limited resources available are typically applied to the issues surrounding the illness itself, such as hospitalization, medication, therapy, and living arrangements (Schulze & Rossler, 2005). The idea that some parents may also need help may not be immediately apparent to mental health providers (Cook, Lefley, Pickett, & Cohler, 1994).

Symptoms of schizophrenia can include hearing voices, paranoia, disordered thinking, and delusions of control (American Psychiatric Association, 2000). These symptoms can cause the ill family member to behave so differently, that he may seem like a bizarre stranger to the other members of the family, intensifying the family's experience of loss and yearning for the person they knew before illness onset.

As previously discussed, the stress from caretaker burden can be great in the parents of children with a severe mental illness. It is important to note, however, that the grief reaction due to the loss of a child is quite different from the stress of caretaking, although there may be overlap in emotions experienced, such as sadness and anger. This dissertation is intended to further our understanding of grief due to the loss of a child to severe mental illness.

The parents of children suffering from an SMI know grief and hope intimately, as their children experience improvement and relapse time and again (Miller et al., 1990;

Pejlert, 2001; Tuck et al., 1997; Karp & Tanarugsachock, 2000). During an acute episode, the presence of the illness is all too apparent. At this time, the parents may experience intense loss, anxiety, fear, sadness, helplessness, and hopelessness. After the child becomes more psychologically stable, the parents may engage in denial of the chronic nature of the mental illness, hoping their child is now 'well' and life will return to the way it was before illness onset. This emotional roller coaster can be difficult for families to handle, especially if they do not have supportive resources to assist them (Miller et al., 1990; Pejlert, 2001; Tuck et al., 1997; Karp & Tanarugsachock, 2000).

Parents whose children suffer from an SMI, such as schizophrenia, experience grief in several ways. They grieve for the child they knew and enjoyed before the illness' onset. Since the child is likely to be an adult, the parents may be besieged by more intense grief than if the child was much younger, experiencing more somatic symptoms, problems with sleep and appetite, guilt, depression, and despair (Rubin, 1990). The parents are faced with the daily conflict of having their child physically present, but behaving as a stranger in unpredictable ways (Wasow, 1985; Ryan, 1993; Tuck et al., 1997; Milliken, 2001; Osborne & Coyle, 2002; Miller, 1996; Karp & Tanarugsachock, 2000; Jones, 2004). They are still attached to the mental representation they have of the child, but the reality is very different. They grieve for the destroyed hopes and dreams that they held for the child (Wasow, 1985; Ryan, 1993; Tuck et al., 1997; Howard, 1998; Karp & Tanarugsachock, 2000). The parents also grieve for their own lost future and freedom, as caregiving continues well past the anticipated length of time (Pejlert, 2001; Wasow, 1985; Ryan, 1993; Tuck et al., 1997; Milliken, 2001; Howard, 1998). Mothers, especially, have a heavy burden of care for the ill child (Millken, 2001; Howard, 1998;

Nystrom & Svensson, 2004). Some parents feel as if they are neglecting their other children to care for the ill child (Howard, 1998).

There are many stressors that can increase the pain that the grieving parents endure. The parents often are living in a state of chaos and are troubled over the way their child currently behaves (Wasow, 1985; Nystrom & Svensson, 2004; Milliken, 2001). The strain of dealing with such a strange and stressful situation on a daily basis often adds tension to the marriage (Nystrom & Svensson, 2004). Having to cover hospital bills, therapy costs, and medications that are not covered fully by insurance can increase financial burden (Wasow, 1985; Howard, 1998). Many parents find that it is so difficult to go out with the child, due to behavior problems, they experience distress over perceived social isolation (Wasow, 1985; Milliken, 2001; Howard, 1998; Solomon & Draine, 1996). The parents often report feelings of shock, guilt (Pejlert, 2001; Wasow, 1985; Milliken, 2001; Miller, 1996; Karp & Tanarugsachock, 2000), anger (Wasow, 1985; Miller, 1996; Karp & Tanarugsachock, 2000), sadness (Pejlert, 2001; Nystrom & Svensson, 2004; Miller, 1996; Karp & Tanarugsachock, 2000), depression, fear, low self-esteem (Howard, 1998), and disbelief (Karp & Tanarugsachock, 2000), as well as rising and falling hope (Miller et al., 1990; Pejlert, 2001; Tuck et al., 1997; Karp & Tanarugsachock, 2000).

Many of the grieving parents also endured the additional stress of a lack of understanding from family, friends (Wasow, 1985; Milliken, 2001; Howard, 1998; Solomon & Draine, 1996; Miller, 1996; Karp & Tanarugsachock, 2000), and mental health professionals (Pejlert, 2001; Milliken, 2001; Wasow, 1985; Holden & Lewine, 1982). Some parents were blamed by mental health professionals, from whom they

sought guidance, for causing their child's illness (Lewine, 1979). For some parents, participation in the legal system was required when their child would get into legal trouble (Wasow, 1985). The distress of chronic grief caused physical illness for many parents (Wasow, 1985).

Similar to the chronic nature of the child's illness, the parents' grief is very chronic, although delayed in onset (Miller et al., 1990; Pejler, 2001; Tuck et al., 1997; Miller, 1996; Karp & Tanarugsachock, 2000). Parental grief may be delayed due to several factors: parents excused the child's behavior at first as adolescent rebellion, as receiving a diagnosis often took years (Miller et al., 1990; Wasow, 1985; Tuck et al., 1997; Milliken, 2001; Nystrom & Svensson, 2004; Osborne & Coyle, 2002; Solomon & Draine, 1996; Karp & Tanarugsachock, 2000); disbelief and denial protected parents from facing the diagnosis; and parents clung to the hope that the child would improve. Once grief occurred, many parents found it difficult to find closure for their grief when their child was very much alive and present (Jones, 2004). The child may not be the same person as before the illness, but there was no memorial service, burial, or public acknowledgment of the parents' loss to aid closure. The only solace some parents found was from attending support groups where they could discuss their experiences with others who understood (Milliken, 2001; Nystrom & Svensson, 2004). Over time, some parents eventually found some degree of personal growth or acceptance of their child's illness (Milliken, 2001; Nystrom & Svensson, 2004; Karp & Tanarugsachock, 2000).

While there are some studies that have examined the impact of having a child with an SMI, there is still a dearth of studies to address this situation. This is an area that needs to be investigated more fully to further understand the prevalence, nature, and

course of grief in reaction to SMI in order to make sure that parents are given the support they need to deal successfully with their child's illness and often difficult symptoms (MacGregor, 1994). Because the parental loss may be unrecognized by others and involve stigma, concealment, or avoidance, the parent's grief may be disenfranchised, resulting in diminished mental or physical health (Godress, 2005).

Parental grief due to the severe mental illness of a child may affect the health of the parent and the health of the attachment relationship between the child and parent. In turn, the attachment relationship between the parent and child may affect the level of grief the parent experiences. Godress and her colleagues (Godress et al., 2005) decided to study these impacts and identify the important aspects of grief for the parents. The results indicated that the parents of children with an SMI do suffer from significant levels of grief. The authors found that parental grief was significantly inversely correlated with the number of years since the diagnosis, which suggests that the parent's grief began with the diagnosis. The trend of parental grief began at about one year since diagnosis, decreased by the third year, increased to the year one level by the fifth year, then steadily decreased again afterwards. The trend line rather fittingly resembled a roller coaster. The lowest levels of grief appeared after the ten-year period from diagnosis.

The parents were shown to experience continuous emotional distress, a preoccupation with the mentally ill child, problems adjusting to the loss, intrusive thoughts and feelings, and active attempts to avoid any thoughts or feelings pertaining to the child and the mental illness. The authors also suggested that some aspects of the parent's grief diminish over time, but not all. Unfortunately, the authors did not specify

which aspects of grief improved over time or did not. The grief appears to fluctuate over the life course.

Suggested factors that complicate the complete processing of the parent's grief include the absence of an actual body to mourn and final ritual, the changes to the mental representation of the loss over time, and that some of the loss is unanticipated. The authors also found that the psychological well-being and physical health of the parents were affected adversely by the grief and loss, as was emotional distress. However, the authors also found that grief was less in parents who had a secure attachment bond with their child, as demonstrated from a comparison of the grief measure results to those of the attachment measure ($r = -0.36, p < 0.01$). Parents with an anxious ambivalent attachment with their child reported greater grief ($r = 0.27, p < 0.05$).

Atkinson (1994) compared the grief and loss that occurs in parents with a child who suffers from schizophrenia to the grief of parents of adult children who die or suffer a traumatic brain injury that affects the child's personality. Measures of grief, depression, anxiety, and substance abuse were obtained using semi-structured interviews and self-report. Unfortunately, the makeup of the small sample (25) was heavily Non-Hispanic White and all of the participants were members of support groups. A larger, more diverse, sample in the future would be helpful, although this study did match the families for race and SES, the children for sex and age at illness, injury, or death, and the parents for current age.

Atkinson found significant differences in grief reactions and in the way that the parents coped. The parents of children with schizophrenia suffered from later (1-5 years), but more chronic, grief than parents who lost a child to death (Miller, 1990) or to

head injury. The mean grief scores for parents of children with schizophrenia more than doubled (23.8 to 53.8, Mental Illness Version – Texas Inventory of Grief) between diagnosis and current grief. The intensity of the grief due to the death of a child was found to decrease over about five years (61.5 to 28.8, MIV-TIG). There were no significant differences between the groups on measures of depression or anxiety.

Grief versus depression

As differentiated in the Diagnostic and Statistical Manual (DSM-IV-TR, American Psychiatric Association, 2000), grief and depression are two separate experiences that can have overlapping symptoms at times, but are not the same concept. In other words, a person can have grief without depression or depression without grief. The DSM-IV-TR (American Psychiatric Association, 2000) differentiates grief from major depression, suggesting that major depression not be diagnosed unless the symptoms of grief continue unabated for two months after a loss. Grief is considered to be a normal psychological reaction to the loss of a loved one, with symptoms such as feelings of sadness, insomnia, loss of appetite, and weight loss that are also common in depression. The main differences between normal grief and depression, according to Worden (2002), are that in grief there is no loss of self-esteem, guilt is typically only associated with certain aspects of the loss, and any sadness experienced is considered normal and time limited. Grief is the intense, painful, normal personal experience of the loss of someone, or something, a person cared about and is typically resolved over time.

A preliminary study of unresolved grief in families of seriously mentally ill patients
(Miller, Dworkin, Ward, & Barone, 1990)

Perhaps the best investigation of parental grief due to severe mental illness is that of Miller and his colleagues (Miller et al., 1990), who conducted a study of unresolved grief in the relatives of patients with schizophrenia and bipolar disorder.

The authors of the study believed that an appropriate measure did not currently exist for assessing grief related to mental illness. They created the Mental Illness Version of the Texas Inventory of Grief (MIV-TIG), which they based on the Texas Revised Inventory of Grief. The new measure's internal consistency was found to be high (alpha coefficient part 1=.82; alpha coefficient part 2=.92), but the validity of the measure needs to be further examined, since there were only 48 final participants in the study.

Both initial and present grief over the loss of the relationship with the mentally ill relative were examined in the study. Miller's group found that the relatives did indeed suffer from grief and that it was similar in magnitude to relatives who lost a loved one to death. However, they noted that initial grief was fairly low and present grief was much higher in the group with a mentally ill family member. They discovered that the relatives tended to grieve chronically, as hope would rise and fall. It was also revealed that the progress of grief was influenced by a delay in comprehending the seriousness of the illness and how it would progress over time. The experience of grief was found to be similar regardless of whether the child suffered from schizophrenia or bipolar disorder, so the different symptoms of the illnesses did not appear to impact level of grief. Oddly enough, the chronic nature of the illness and the severity of the illness were not good predictors of grief in the family members.

Lost Potential

Lost potential has been studied as a possible factor that may contribute to suicidal behavior, particularly in schizophrenia patients (Lewine, 2004). For some with schizophrenia, high expectations and ample opportunities existed before illness onset. After illness onset, the high expectations may still be present, but impairment due to the symptoms of schizophrenia limits the opportunities available. Surprisingly, those from more advantaged backgrounds may be more at risk for depression and suicide due to lost potential than those from less advantaged backgrounds (Lewine, 2004). Research has shown that job expectations are significantly, positively correlated with the socioeconomic status of the ill person's family of origin, depression, and hopelessness (Lewine, 2004). Coming from an advantaged socioeconomic status could actually cause a disadvantage in coping with a vocational loss. At any point in time, 80-90% of schizophrenia patients are unemployed, adding to family burden.

Impact of caregiver burden

While severe mental illness may impact the family as a whole, parents often must fulfill the role of caregiver to the adult child. This role can be a significant burden when a child has a severe mental illness. This experience is separate from grief due to the loss of the child known before the illness or vocational lost potential due to the lost expectations of employment and self-sufficiency held by the parent for the child. Caregiver burden involves caring for the adult child financially, medically, legally, and psychologically, as well as attending to the typical activities of daily living for them (Cook, Lefley, Pickett, & Cohler, 1994; Mendenhall & Mount, 2011). For many parents, this amounts to never-ending parenting.

One study (Bulger et al., 1993) examined the relationships between parents and children with schizophrenia, as well as how these relationships affect the perception of burden from caregiving. The authors interviewed 60 parents who were caregivers of adult children with chronic schizophrenia or schizoaffective disorder, using a structured interview. Nineteen were recruited from a support group and the other 41 participants were randomly recruited by asking permission of patients at a community mental health center to contact their caregiving parent. While most of the caregivers were mothers (85%), there was very good diversity of race, education, and income. This diversity enhanced the potential generalizability of the results to parents of various races, educational levels, and socioeconomic statuses. In this study, most of the patients lived at home (60%). Various structured interviews were used in gathering information from participants. Hierarchical regression analyses were performed to determine which factors impacted the perception of burden for the caregivers. The results indicated that relationship factors, particularly regarding intimacy and conflict, were more highly associated with the perception of burden than were the level of symptom severity or the intensity of caregiving. In addition, 18% of the parents identified “sorrow over the child’s suffering and wasted life” as the hardest part of being a caregiver. “A less rewarding relationship with the child” was endorsed by 25% of caregivers, who believed that their child had become unpredictable, dependent, and argumentative. Finally, 45% said that after a conflict with their child, both the parent and child had a high level of tension and distress, with the parent’s reaction being depression, guilt, worry, or anger.

Jungbauer and his associates (Jungbauer et al., 2004) interviewed 51 parents of children with schizophrenia to identify what is lost to the patient and family. Parents for

this qualitative study were recruited through patients in psychiatric inpatient, outpatient, and day care facilities. While this selection process is helpful because it covers experiences in various mental health settings, the parents could still be considered self-selected. As with many other studies of this nature mothers had the highest burden of care, based on in-depth interviews, and comprised the majority of the participants (42 of 51). Experienced, trained psychologists conducted the narrative interviews of parents. The authors found that many parents were concerned about the inability of the child to detach from the parents and develop an independent life; at the time of the study, 41% of the patients lived with their parents. One-third of the parents reported their child had difficulty managing financially. The authors stated that parents often experienced guilt for wanting their children to live on their own, allowing parents and children to have their own lives. The intensity of the adult-child relationship was found to have increased after illness onset, resulting in never-ending parenting. This type of parenting is anticipated to last for as long as the parents live, and includes such continued activities as feeding, cleaning, and financially supporting the adult child. It also includes medication monitoring and getting the adult child to appointments with doctors, therapists, and social workers. A final activity of this parenting involves securing future care and support for the adult child in the event of the parents' deaths. Many parents identified having continual worry and fear about what will happen to their child after they are no longer alive.

The study also described how both parent and child suffered from diminished social contacts and support due to the intensity of this relationship. Parents reported they isolated due to the fear of stigma and lack of understanding; the child isolated due to the

disappearance of friends who could not deal with the illness. The dependence of the child on the parents is not only due to practical issues, but also to emotional issues. It is as if the child has lost the feeling of a secure base, due to the illness, and must seek proximity to the parents, rather than explore the world outside. As when younger, the parents once again become the most important individuals in the adult child's life. The adult person who was developing disappears and is lost, as the adult child reverts to the dependency of childhood.

The parents in this study also identified a financial loss due to the child's illness, as they had to continue to support the child into adulthood. Parents who were uncertain as to whether or not their children could find a job and support themselves mentioned resentment and anger toward the child. Some parents shared that they felt trapped between the feeling of responsibility for their child's welfare and the desire to distance themselves from the constant burden. Social comparisons to friends or other family members were associated with bitterness and sadness. The inability of the ill child to detach, explore, and develop led some parents to grieve the person they thought the child would become and the relationship they thought they would have. The parents not only grieved the lost child, but also grieved the lost life they expected to experience, which was anticipated to include relief from child care, time for their own interests, and eventually the retirement they had envisioned for themselves. Jungbauer's study enhanced the available information regarding the effects of a child's severe mental illness on the parents. The narrative format, however, did not provide enough helpful information regarding the distribution of the difficulties endorsed by the parents.

Limitations of current research

The few studies that have addressed the effects on the parents of having a child with an SMI are plagued with similar limitations that need to be addressed and overcome in future research. Many of the studies are descriptive in nature and could have various interpretations to the participants' stories (Pejlert, 2001; Wasow, 1985; Ryan, 1993; Howard, 1998; Nystrom & Svensson, 2004; Osborne & Coyle, 2002; Miller, 1996; Karp & Tanarugsachock, 2000). As is usual with this type of research, data for some studies was obtained through self-report surveys or interviews (Holden & Lewine, 1982; Lewine, 2004). Others are plagued by very small sample sizes (Miller et al., 1990; Pejlert, 2001; Wasow, 1985; Ryan, 1993; Tuck, 1997; Milliken, 2001; Howard, 1998; Nystrom & Svensson, 2004; Osborne & Coyle, 2002; Miller, 1996; Karp & Tanarugsachock, 2000; Jones, 2004; Holden & Lewine, 1982; Lewine, 2004) and are low in power (Miller et al., 1990; Solomon & Draine, 1996; Pejlert, 2001; Wasow, 1985; Ryan, 1993; Tuck, 1997; Milliken, 2001; Howard, 1998; Nystrom & Svensson, 2004; Osborne & Coyle, 2002; Miller, 1996; Karp & Tanarugsachock, 2000).

The lack of diversity in the demographics of the participants is another common deficit of these studies, as well as a low rate of participation by fathers (Solomon & Draine, 1996; Miller et al., 1990; Pejlert, 2001; Ryan, 1993; Tuck, 1997; Milliken, 2001; Howard, 1998; Nystrom & Svensson, 2004; Osborne & Coyle, 2002; Miller, 1996; Karp & Tanarugsachock, 2000; Holden & Lewine, 1982; Lewine et al., 1982; Lewine, 2004). In addition, some studies utilized tasks or measures with unknown psychometric properties (Sprong et al., 2007; Lewine, 2004). These limitations severely curtail generalizability of the results to the population of individuals affected by severe mental

illness as a whole. Although these studies possess significant limitations, they do shed light on the grief experiences of parents who have lost a child to SMI.

Summary and hypotheses

Miller and his colleagues (1990) demonstrated that grief exists in the parents of adult children with a severe mental illness and that the grief is chronic. As discussed earlier, this grief is unlike depression, which is a serious mental illness that can occur even under the best of circumstances. This important study should be replicated and extended to examine the existence and implications of other factors that may impact parental grief such as possible sex differences in the offspring; and sex, age, race, and education level of the parents. It is possible that mothers and fathers may grieve differently.

In addition, the presence and impact of lost potential should be examined as it applies to parents. It is possible that parents may experience feelings of lost potential related to the expectations they held for their child regarding education, family, independence, and career.

Clearly, parents of adults with severe mental illnesses experience a sense of loss and grief that seems related to the onset of their adult child's psychiatric disorder. The time course of this grief may be opposite to that of grief in response to physical loss of a child and is exacerbated by, but different than, the stresses of unending caretaking. Furthermore, some portion of the grief may be due to the parents' loss of expectations both for their child and for themselves. The purpose of this dissertation is to examine with greater rigor the relationships among grief, duration of the child's illness, lost

potential, parent sex, child sex, and caregiver burden in order to better understand the nature of grief to loss of a child to a psychiatric disorder.

These important issues have only been examined on a small scale and many questions remain to be answered. It is important to continue the research on parental grief due to mental illness in order to educate mental health professionals and parents on the impact it has and to improve our ability to help parents cope.

To investigate some of these unknowns, the following hypotheses will be examined:

- 1. Parents of adult children with severe mental illness experience grief symptoms that begin after receiving a diagnosis. Intensity of grief will be highest for parents of children with illness duration of 4 to 6 years since diagnosis. Intensity of grief will be lowest for parents of children with illness duration of greater than six years since diagnosis.*
- 2. Sex of parent and sex of child will function as moderators between time since diagnosis (duration) and grief.*
- 3. These relationships between grief, time since diagnosis, sex of parent, and sex of child will remain significant even after controlling for caregiver burden.*
- 4. Vocational lost potential will function as a moderator of parental grief. A higher level of vocational lost potential will be associated with a higher level of grief intensity, due to the parent's feelings of loss for the child's future expectations.*

RESEARCH DESIGN AND METHODS

Study Design

This cross-sectional study was designed to examine the intensity and possible moderators of parental grief due to severe mental illness. Grief is likely to be a complex experience, affected by the parents' individual personality characteristics and histories. It is unlikely that such a complex concept would involve mediator variables that would neatly account for the total relationship between duration of illness and grief intensity. Qualitative variables such as sex, race, age, and intensity of lost potential experienced may moderate the direction or strength of the relationship between the duration of the child's illness and intensity of grief, however.

Participants were asked to anonymously complete a grief measure, sociodemographic questionnaire, lost potential survey, and caretaker burden measure. Participation required an hour or less.

Participants

Participants were parents of adults with a severe mental illness, such as schizophrenia, schizoaffective disorder, bipolar disorder, or major depression. The parents were recruited through the National Alliance on Mental Illness (NAMI-KY), which is a state affiliate of a national support and advocacy group for those affected by mental illness. There was a special effort to recruit fathers, since they typically participate less frequently than mothers in research studies. Each father attending a NAMI event was approached by the investigator and informed about the study and the

importance of sharing his experiences. Additional surveys were given to mothers attending NAMI events alone, with the request that the surveys be given to the child's father. Participants were recruited from NAMI-Kentucky members by making questionnaires, with a description of the study, available to them during NAMI meetings. A brief summary of the study, by the researcher, was also provided at the beginning of each meeting. Included with the questionnaires were stamped, self-addressed envelopes for a confidential, anonymous reply. These questionnaires were also made available at NAMI-KY board meetings and at the NAMI national convention. Approval for this study was obtained from the IRB of the University of Louisville. Participants were not compensated for their time. Many enthusiastically wanted to participate to possibly help others in the same situation; none asked about remuneration for their assistance.

Participation was voluntary.

After collecting data in 2009, 2010, and part of 2011, recruitment was ended after data from 78 participants had been received. As evidenced by most of the studies in this area, it is very difficult to recruit large numbers of parents to participate. In an effort to involve as many parents as possible, the investigator personally attended NAMI support meetings, talks, and annual walks. Hundreds of NAMI members statewide attend the annual walks, especially the one in Lexington. The investigator also attended the Lexington NAMI support group meetings every Sunday and three different Louisville NAMI support group meetings twice a month. The study was presented and parents recruited at both the Louisville and Lexington Family-to-Family classes and at the NAMI Louisville board meeting. Surveys were carried to the national NAMI convention by the

NAMI Louisville president at the time. Information about the study was also included in NAMI newsletters, as well.

Of the study participants, approximately three-fourths of parents (77%) were female. Only 38.5% of the adult children were female, however. The study participants were predominantly Non-Hispanic White (90.9%), as were the children (94.8%). The majority of the parents had some college education (82.1%), as did the children (60.3%). The parents were typically married (70.5%), although 17.9% were divorced. As might be expected due to the typical age of onset for severe mental illness, most of the parents were at least 50 years of age, with 45.5% age 65 or older. Of the children, 13% were age 50 or older.

Measures

Sociodemographic Form

The following sociodemographic information was collected by self-report of the parent: Parent's sex, parent's race, parent's years of education, parent's age, parent's marital status, whether both the child's parents are alive, child's sex, child's race, child's years of education, child's current age, child's diagnosis, whether the child is on medication and the name of the medication, the duration (in years) of the child's illness (based on 1st hospitalization or when diagnosis received), whether the child sees a therapist and how often, whether the child is employed, the duration of the child's longest employment, type of child's employment, and whether the child is adopted or biological.

Duration of illness from the sociodemographic form was collected based on number of years, then converted to one of three time frames: 0 to 3 years (group 1), 4 to 6 years (group 2), >6 years (group 3). Converting the duration to time frame variables

allowed a one-way between-groups ANOVA to be performed on duration of illness to assess its impact on parental grief (MIV-TIG score), with the a priori prediction that grief would be significantly greatest for the 5-year group.

Mental Illness Version of the Texas Inventory of Grief (MIV-TIG)

The Mental Illness Version of the Texas Inventory of Grief (MIV-TIG; Miller, Dworkin, Ward, & Barone, 1990) was developed for use in the assessment of grief in family members of the mentally ill. It consists of 24 questions, 8 on past behaviors and 16 on current feelings, utilizing a 5-point Likert scale. Participants read the 24 statements and selected the best response related to their personal experience. Responses can range from Completely False to Completely True. Each question can have a score of 1 (completely false) to 5 (completely true), for a total score range of 24 to 120. The higher the total score, the higher the level of grief. This measure was used to quantify the dependent variable of grief. This particular measure was chosen because of its specificity to grief due to severe mental illness, as well as its reliability, validity, and length. To address possible inadequate variability in the 'duration of illness' results, the parents were also asked when their grief began, with careful attention paid to not suggest any particular point in time for them. It is possible that NAMI-KY members may have more years since their children were diagnosed, since NAMI-KY members are likely to be members for many years. This factor could heavily weight the '>6 years' group of illness duration. To address this issue, the parents were asked to retrospectively rate their grief intensity on a scale of 1 (low) to 5 (high) for the following time frames after their child's diagnosis: 0 to 3 years (group 1), 4 to 6 years (group 2), and >6 years (group 3). This request was added to the bottom of the MIV-TIG measure.

The MIV-TIG is a revision of the Texas Inventory of Grief. The authors had the revised instrument reviewed by four experts in grief. The instrument's internal consistency was measured utilizing Cronbach's alpha for the whole sample, for split-half reliability, and for deletion of each item from the measure. The internal consistency was high for the measure's section on past symptoms (alpha coefficient = .82; split-half correlation = .59), with the removal of any items causing very minimal differences in the alpha coefficient. The internal consistency was very high for the measure's section on present symptoms (alpha coefficient = .92; split-half correlation = .89), with no improvement to the alpha coefficient by the removal of any item.

Lost potential survey (Lewine, 2004)

The grief measure designed by Miller and his colleagues (MIV-TIG, 1990) has some general questions applicable to lost potential, however, another measure, specific to parental job expectations related to lost potential (Lewine, 2004), was also employed. This Lost Potential survey was originally devised to quantify feelings of lost potential in patients with schizophrenia (Lewine, 2004). It was determined that patients from a higher socioeconomic status suffered more feelings of lost potential. This was attributed to the high expectations that existed before illness onset and the lowered opportunity to reach those expectations after becoming ill. The measure was revised to assess the feelings of lost potential in the parents of adult children with a severe mental illness. The measure consists of five questions that explore the parents' feelings when they realized their child was ill, the expected accomplishments they had for the child, the types of potential lost due to the child's illness, and ways the parents have tried to cope with the losses.

The parents were asked to designate the loss that is the most disappointing and to rate the level of disappointment on a scale of 1 (none) to 5 (intense). In addition, the parents were asked to state the job, or type of job, that they expected their child to have at the time of assessment were it not for the psychiatric illness, as well as the job the child currently has. Jobs were coded according to the Watt (1976) tables of occupations, which have values assigned for various occupational levels from 0 (unemployed) to 7 (professional). The difference between these two jobs quantified the amount of vocational lost potential the parents experienced related to the child and the illness. This score was calculated so that the higher the score, the greater the “lost potential”. Specifically, Vocational Lost Potential was calculated by subtracting the current actual job from the expected job. Since many of those with a severe mental illness will be unemployed, the difference score was often the same as the job expectation before illness onset. The lost potential score was converted to two groups: group 1, “low” (scores of 0 to 3) and group 2, “high” (scores of 4 to 7).

Thresholds Parental Burden Scale (Cook & Pickett, 2001)

The Thresholds Parental Burden Scale (Cook & Pickett, 2001) allows for a total burden score, with higher scores suggesting a high level of burden. This instrument was developed to assess the burden that parents who live with a severely mentally ill child experience. It presents twenty-nine problem statements that the parent rates on a six-point Likert scale, from “strongly agree” to “strongly disagree”. The measure allows for a total burden score, with higher scores suggesting a high level of burden. Total scores can range from 29 to 174 for the dependent variable of burden. It also contains subscales for feelings of ongoing connection, preoccupation, ongoing responsibility, inability to

manage behavior, family disagreement, and concern over reoccurrence of symptoms and the child's future. The measure yielded a Cronbach's alpha of .80, demonstrating good internal reliability when measuring the dependent variable of burden.

Procedures

Parents decided whether to participate or not after the measures were made available to them at NAMI meetings. This organization represents over 1,300 members/households, with 22 affiliate groups throughout Kentucky. The study description letter included with the measures stated that participation was voluntary and was used as evidence of consent. The stamped return envelopes provided had the return address already noted, which matched the study submission address. This made it unlikely that a participant would insert his or her own return address on the envelope and void the condition of anonymity. There was no way for the investigator to know which parents completed the study. The participants were asked to complete the measures in the following order: sociodemographic form, lost potential survey, Thresholds Parental Burden Scale, and the Mental Illness Version – Texas Inventory of Grief (MIV-TIG). This order was chosen so that the most affect-laden questions would be dealt with last, to prevent contamination of other measures. There should have been only minimal risk to the participants, but they were given the Seven Counties 24-hour crisis hotline (1-800-211-0446) to call if completion of the measures triggered intense affect. This phone number was listed in the cover letter for the study. Approval for the study was obtained from the university IRB committee.

Data Analysis

The number of participants required for the completion of this study was obtained earlier from the G*power3 program for power analysis (Faul, Erdfelder, Lang, & Buchner, 2007). Two-way and three-way between-groups ANOVAs were used to test most of the hypotheses. A one-way ANOVA was used to test the main hypothesis related to duration, so it was selected to determine the necessary sample size to enable analysis of main effects and interactions. Most of the G*power3 hypothesis calculations determined a sample size equal to that suggested for the main hypothesis, however. A medium effect size of 0.25 was specified, with power of 0.80 and an alpha of 0.05. Based on these parameters, the power analysis indicated a suggested sample size of 159 participants for the study.

ANOVA analyses were performed to investigate the main and interaction effects between the dependent variable of grief and the independent variables of duration of illness, sex of parent, sex of child, and lost potential. Assumptions appropriate for a fixed-effects model of ANOVA were examined for violations. The assumption of a normal distribution of grief scores was not violated, as demonstrated by the following graphs:

FIGURE 1

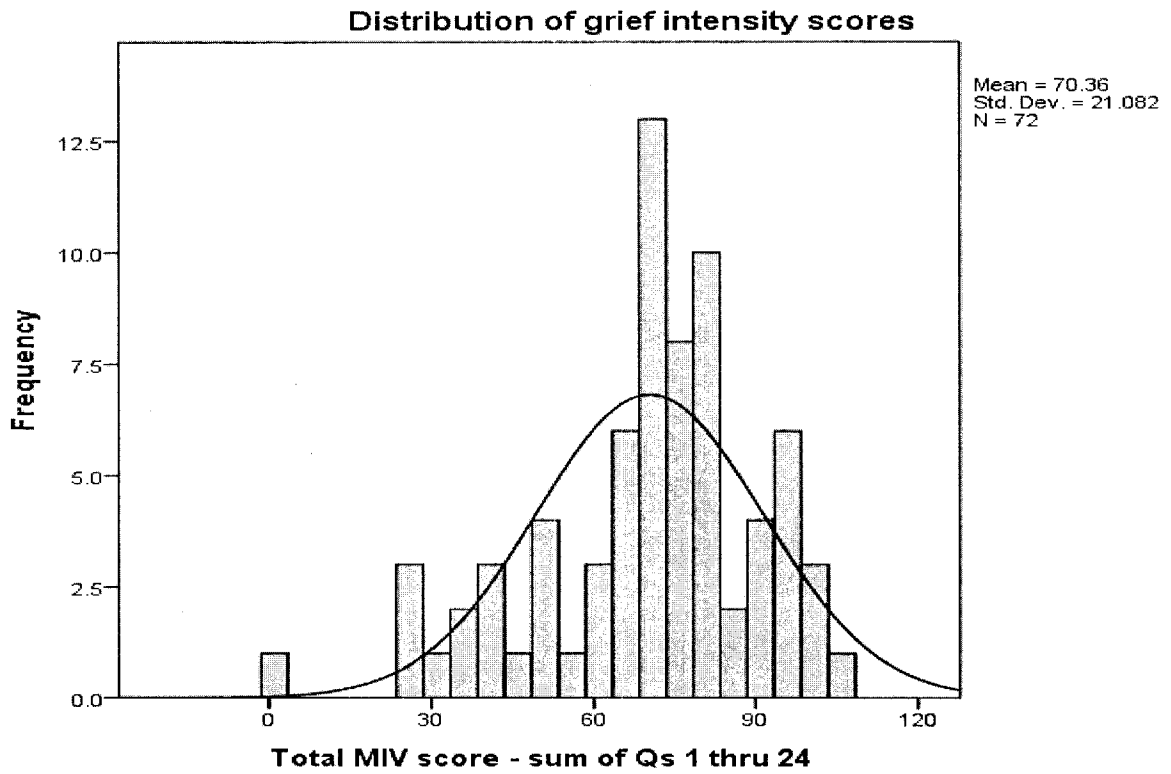
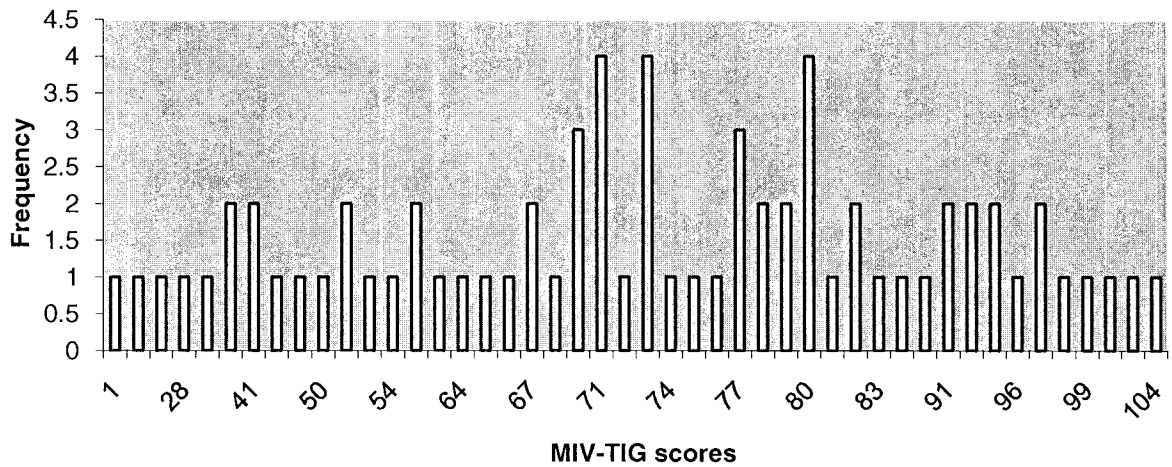


FIGURE 2

Detail distribution of grief scores



The assumption of homogenous variances for each ANOVA analysis was examined with Levene's Test of Equality of Error Variances. Since this study was an

anonymous sampling of participants, it was not possible to ensure that all the group sizes were equal. If an ANOVA analysis violated this assumption, it is noted in the results for that analysis.

The assumption of independent observations did not initially appear to be violated, since each participant's score was independent of any other participant's score. In addition, there were no repeated observations involved in this study. A review of the participant data revealed that three couples submitted surveys that were identical to their spouse's, however. Since the two-parent survey responses were not independent, they were removed from the analyses to avoid violation of the assumption of independent observations. The study analyses were conducted with and without these six participants to determine whether or not that data had an impact on the results. We eliminated these six participants from the primary analyses, although we briefly report the results of the analyses including them. By removing these participants, the assumption of independent observations was not violated.

Data were also reviewed for accuracy and some corrections were made. These corrections involved retrospective ratings of the intensity of grief at 0 to 3, 4 to 6, and greater than 6 years since diagnosis. A few participants endorsed ratings for periods of time not yet experienced, such as selecting ratings for 4 to 6 years and greater than 6 years when it had only been 0 to 3 years since their child's diagnosis. These responses were changed to 'not applicable', since they were not valid responses. Regarding missing data, analyses excluded missing values analysis by analysis.

RESULTS

Descriptives

Descriptive statistics were generated in order to describe the sample and verify that the assumptions of each subsequent statistical analysis were not violated. The frequencies of categorical variables were reported and reviewed. These variables included the parent's and child's current ages, race, sex, and years of education, as well as the parent's marital status (Table 1). In addition, the means, standard deviations, and range of scores of continuous variables were examined. These variables included the child's duration of illness, and scores on the MIV-TIV, lost potential survey, and parental burden scale (Table 2). Based on participant responses, the average duration of a child's illness was over six years (6.4).

TABLE 1
Sample Demographic Frequencies

	Number	Percentage
Parent sex		
Male	15	20.8%
Female	57	79.2%
Child sex		
Male	44	61.1%
Female	28	38.9%
Parent race		
White	64	88.9%
Black	2	2.8%
Hispanic	1	1.4%
Asian	1	1.4%
Other	1	1.4%
Declined	3	4.1%
Child race		
White	67	93.0%
Black	2	2.8%
Hispanic	0	0.0%
Asian	1	1.4%
Other	0	0.0%
Declined	2	2.8%
Parent Years of Education		
0 to 8	0	0.0%
9 to 12	12	16.7%
GED	0	0.0%
13+	60	83.3%
Child Years of Education		
0 to 8	0	0.0%
9 to 12	14	19.4%
GED	13	18.1%
13+	45	62.5%
Parent Marital Status		
Single	1	1.4%
Married	51	70.8%
Divorced	12	16.7%
Widowed	8	11.1%
Parent Age		
30 to 49	4	5.6%
50 to 64	36	50.0%
65+	31	43.0%
Declined	1	1.4%
Child Age		
Under 30	30	41.7%
30 to 49	31	43.0%
50 to 64	10	13.9%
Declined	1	1.4%

TABLE 2
Sample Descriptive Statistics

	N	Mean	Standard Deviation
Duration of Child's Illness (range: 0 to 8)	72	6.4	2.5
Thresholds Parental Burden Scale (range: 29 to 174)	72	100.1	27.6
MIV-TIG total (range: 24 to 120)	72	70.4	21.1
Vocational Lost Potential (range: 0 to 7)	72	3.1	2.6

Hypothesis testing analyses

Hypothesis 1: Parents of adult children with severe mental illness experience grief symptoms that begin after receiving a diagnosis. Intensity of grief will be highest for parents of children with illness duration of 4 to 6 years since diagnosis. Intensity of grief will be lowest for parents of children with illness duration of greater than six years since diagnosis.

A one-way (duration) ANOVA on the intensity of grief, as measured by the Mental Illness Version of the Texas Inventory of Grief (MIV-TIG), was conducted to test Hypothesis 1. The results indicate that the effect of duration of illness on grief intensity approaches the conventional level of statistical significance [$F(2,69)=2.643, p=.078$]. The means, with standard deviations, of grief by duration group are presented below:

TABLE 3
Total MIV Grief Score by Illness Duration Group

	N	Mean	Std. Deviation
0 to 3 years	13	77.4	17.6
4 to 6 years	12	78.7	11.1
Over 6 years	47	66.3	22.9
Total	72	70.4	21.1

Independent-samples t-tests were also conducted to compare mean grief intensity for duration of illness by category. The results of the analyses demonstrated a significant difference in grief intensity between illness durations of ‘4 to 6 years’ (M=78.67, SD=11.13) and ‘greater than 6 years’ [M=66.30, SD=22.94; $t(37.32)=2.67, p<.01$]. The magnitude of the difference in the means was moderate to large (eta squared=.111). The differences between grief intensity for ‘0 to 3 years’ (M=77.38, SD=17.63) and for ‘4 to 6 years’ [M=78.67, SD=11.13; $t(23)=-.22, p=.83$] were not significant. The magnitude of the differences in the means was very small (eta squared=.002). The differences between grief intensity for ‘0 to 3 years’ (M=77.38, SD=17.63) and ‘greater than 6 years’ [M=66.30, SD=22.94; $t(58)=1.61, p=.11$] were also not significant. The magnitude of the differences in the means was small to moderate (eta squared=.043).

A review of the data shows that the parent sample was heavily weighted toward illness durations of greater than 6 years:

TABLE 4
Duration of Child's Illness – Frequency Table

	Frequency	Percent	Valid Percent	Cumulative Percent
No diagnosis	1	1.4	1.4	1.4
< 1 year	6	8.3	8.3	9.7
1 year	2	2.8	2.8	12.5
2 years	4	5.6	5.6	18.1
3 years	2	2.8	2.8	20.9
4 years	5	6.9	6.9	27.8
5 years	5	6.9	6.9	34.7
≥ 6 years	47	65.3	65.3	100.0
Total	72	100.0	100.0	

Of the 72 participants, 47 or 65.3% endorsed illness duration of greater than six years since diagnosis. The other two categories, '0 to 3 years' and '4 to 6 years' were more evenly split, with 18.1% and 16.6% endorsement, respectively.

Hypothesis 2: Sex of parent and sex of child will function as moderators between time since diagnosis (duration) and grief.

A 2 (sex of parent) x 2 (sex of child) x 3 (duration by category) ANOVA was used to test the main and interaction effects of sex of parent and sex of child, as well as duration of illness, on grief intensity, as measured by the Mental Illness Version of the Texas Inventory of Grief (MIV-TIG). The total of questions 1 through 24 were used to represent the level of grief. Participants were divided into three groups according to the duration of the child's illness (Group 1: 0 to 3 years; Group 2: 4 to 6 years; and Group 3:

longer than 6 years). The following table provides the means, standard deviations, and sample size for each group created by the 2x2x3 ANOVA:

TABLE 5
Descriptive Statistics – Intensity of Grief by Parent Sex and Child Sex

Parent's Sex	Child's sex	Duration by Category	Mean	Std. Deviation	N
		0 to 3 years	62.0	12.7	2
	Male	4 to 6 years	70.3	8.0	3
Male		Over 6 years	69.7	24.0	6
	Female	4 to 6 years	93.0	.	1
		Over 6 years	58.3	34.9	3
		0 to 3 years	74.1	16.5	8
	Male	4 to 6 years	79.2	11.4	5
Female		Over 6 years	64.7	27.9	20
		0 to 3 years	96.3	3.1	3
	Female	4 to 6 years	81.3	11.8	3
		Over 6 years	68.3	14.8	18

The ANOVA results reveal statistically insignificant main effects for sex of parent [$F(1,61)=.167, p=.684$], sex of child [$F(1,61)=1.362, p=.248$] and duration of illness [$F(2,61)=2.292, p=.110$] on grief intensity, although duration of illness approached significance. The effect size for sex of parent (partial eta squared=.003) was very small, the effect size for sex of child (partial eta squared=.022) was small, and the effect size for duration by category (partial eta squared=.070) was moderate. The interaction of the sex of the parent, the sex of the child, and the duration of the illness was not significant [$F(1,61)=1.161, p=.285$]; the effect size for the interaction was small (partial eta squared=.019). The results for sex of child [$F(1,67)=2.732, p=.103$], sex of parent [$F(1,67)=.004, p=.948$] and duration of illness [$F(2,67)=1.278, p=.285$] were non-significant.

It must be noted that for this analysis of variance, the assumption of the homogeneity of variances was violated according to Levene's Test of Equality of Error Variances [$F(10,61)=2.459, p=.015$]. Since this study was an anonymous sampling of participants, it was not possible to ensure that all the group sizes were equal. One particular sample group, representing fathers of daughters with illness duration of 4 to 6 years, had only one participant, eliminating any possible variability from that group. For this reason, a simpler interaction was examined regarding the effect of parent sex and child sex on grief intensity, without considering duration of illness. This ANOVA produced more larger cell sizes, but the main effects for parent sex [$F(1,68)=.270, p=.605$] and child sex [$F(1,68)=.043, p=.836$], as well as the interaction effect [$F(1,68)=.175, p=.677$] were all insignificant.

Duration of illness was endorsed at 'greater than six years' by nearly two-thirds of the parents (65%), while child sex was more often male with a ratio of 11:7. Parent sex, by contrast, was 74% female.

Hypothesis 3: These relationships between grief, time since diagnosis, sex of parent, and sex of child will remain significant even after controlling for caregiver burden.

Caregiver burden was controlled because it could co-occur with grief. The following table provides the means, standard deviations, and sample size for each group created by the 2x2x3 ANCOVA, as controlled for parental burden:

TABLE 6
Descriptive Statistics – Intensity of Grief by Parent Sex, Child Sex, and Duration of Illness by Category with Burden controlled

Parent's Sex	Child's sex	Duration by Category	Mean	Std. Deviation	N
Male	Male	0 to 3 years	62.2	12.7	2
		4 to 6 years	70.3	8.0	3
		Over 6 years	69.6	24.0	6
	Female	4 to 6 years	93.3		1
		Over 6 years	58.1	34.9	3
		0 to 3 years	74.3	16.5	8
Female	Male	4 to 6 years	79.3	11.4	5
		Over 6 years	64.6	27.9	20
		0 to 3 years	96.6	3.1	3
	Female	4 to 6 years	81.3	11.8	3
		Over 6 years	68.3	14.8	18

The ANCOVA results indicate statistically insignificant main effects for sex of parent [$F(1,60)=.162, p=.688$], sex of child [$F(1,60)=1.351, p=.250$] and duration of illness [$F(2,60)=2.186, p=.121$] on grief intensity. The effect size for sex of parent (partial eta squared=.003) remained very small, the effect size for sex of child (partial eta squared=.022) remained small, and the effect size for duration by category (partial eta squared=.068) was still moderate. The interaction of the sex of the parent, the sex of the child, and duration of the illness, while controlling for burden, was not significant [$F(1,60)=1.159, p=.286$]; the effect size for the interaction was small (partial eta squared=.019).

It must be noted that for this analysis of variance, the assumption of the homogeneity of variances was violated according to Levene's Test of Equality of Error Variances [$F(10,61)=2.497, p=.014$].

Hypothesis 4: Vocational lost potential will function as a moderator of parental grief. A higher level of vocational lost potential will be associated with a higher level of grief intensity, due to the parent's feelings of loss for the child's future expectations.

The following table provides the means, standard deviations, and sample size for each group created by the 2x2x2 ANOVA:

TABLE 7
Descriptive Statistics – Intensity of Grief by Parent Sex, Child Sex, and Vocational Lost Potential by Category

Parent's Sex	Child's sex	Vocational Lost Potential by Category	Mean	Std. Deviation	N
Male	Male	0 to 3	56.8	22.2	4
		4 to 7	75.1	12.5	7
	Female	0 to 3	60.0	46.7	2
		4 to 7	74.0	31.1	2
Female	Male	0 to 3	67.3	30.2	18
		4 to 7	71.4	13.8	15
	Female	0 to 3	76.1	17.5	11
		4 to 7	71.2	16.0	13

The ANOVA results yielded a statistically insignificant main effect for vocational lost potential [$F(1,64)=1.276$, $p=.263$] on grief intensity. The effect size for vocational lost potential (partial eta squared=.020) was small. The interaction of the sex of the parent, the sex of the child, and vocational lost potential was also not significant [$F(1,64)=.027$, $p=.870$]; the effect size for the interaction was very small (partial eta squared=.000). Including the six removed participants did not change the nature of the findings. The main effect for vocational lost potential [$F(1,70)=.000$, $p=.983$] was non-significant.

Since this study was an anonymous sampling of participants, it was not possible to ensure that all the group sizes were equal. While vocational lost potential was endorsed nearly equally for '0 to 3' (n=35) and '4 to 7' (n=37), child sex was more often male with a ratio of 11:7. Parent sex, by contrast, was nearly 75% female. The number of participants in the eight groups referred to by this ANOVA ranged from two to eighteen.

The two levels of lost potential in the analyses indicate low to moderate (0 to 3) and moderate to high (4 to 7) feelings of lost potential, as described in the following table:

TABLE 8
Descriptive Statistics – Intensity of Grief by Parent Sex, Child Sex, and Vocational Lost Potential by Category

Parent's Sex	Child's sex	Vocational Lost Potential by Category	Mean	Std. Error	95% Confidence Interval	
					Lower Bound	Upper Bound
Male	Male	0 to 3	56.8	10.8	35.2	78.3
		4 to 7	75.1	8.2	58.8	91.5
	Female	0 to 3	60.0	15.3	29.5	90.5
		4 to 7	74.0	15.3	43.5	104.5
Female	Male	0 to 3	67.3	5.1	57.1	77.4
		4 to 7	71.4	5.6	60.3	82.5
	Female	0 to 3	76.1	6.5	63.1	89.1
		4 to 7	71.2	6.0	59.3	83.2

The means for grief based on other variables resulted in interesting findings, as well. Specifically, mean grief intensity was higher for daughters (70.3) as opposed to sons (67.6); mothers (71.5) had higher mean grief intensities than fathers (66.5), regardless of child sex. In addition, the lowest mean grief intensity occurred for fathers of sons (65.9).

Post hoc analyses

Correlations between the intensity of grief (Total MIV-TIG score for questions 1 to 24) and demographic variables were conducted after the a priori analyses. Of all the pairwise correlations, only those between intensity of grief and duration of illness ($r = -.240, p=.043$) and child's current age ($r=-.371, p=.001$) were statistically significant; the older the child and the longer the duration, the lower the level of grief.

A multiple regression analysis was conducted to predict the intensity of grief based on duration of illness, parent sex, child sex, vocational lost potential, child's age, and parent's age. The overall model significantly predicted grief intensity [$F(6,64)=2.248, p=.050, \text{adjusted R squared}=.097$]. As anticipated from the pair-wise analyses, the results of the model indicated that child's current age made a statistically significant unique contribution to the prediction of grief intensity ($p=.017$). Specifically, child's age explained 7.7% of the variance in grief intensity and demonstrated a negative relationship with grief. In other words, grief intensity was higher when the child's current age was lower. None of the other independent variables examined, including duration of illness, reached significance. Since child's age and duration of illness both share the common element of the passage of time, a correlation analysis was conducted to determine the significance of the relationship between the two variables. Child's age and duration of illness were significantly positively correlated ($r =.220, p<.033$).

The relationship between the dependent variable of grief intensity and the independent variables selected appears to be linear. Although the results of the ANOVA analysis on grief intensity and duration of illness demonstrated nearly significant differences between duration of illness categories, this result is largely due to the drop in

grief intensity after six years. The multiple regression analysis indicated an insignificant predictive relationship between grief intensity and duration of illness, although duration of illness accounts for 2.2% of the variance in grief intensity. These factors suggest that the nonlinear model of grief intensity originally hypothesized should be revised to fit the linearity of the multiple regression model.

DISCUSSION

Hypotheses

It was hypothesized that grief intensity would be highest for the '4 to 6 years' since diagnosis duration group. It was also hypothesized that grief intensity would be lowest for the 'greater than 6 years' duration group. Based on the results of the ANOVA, the mean grief ratings were consistent with the hypothesis, approaching a conventional level of statistical significance. In addition, the independent-samples t-tests indicated that a significant mean difference exists between illness durations of '4 to 6 years' and 'greater than 6 years'. The pattern of means also supports the hypothesis, but a review of the data suggests that the statistical significance is due to the sharp decrease in grief intensity after 6 years. It should also be noted that the majority of study participants endorsed an illness duration of greater than six years. In addition, the multiple regression analysis indicated that duration of illness accounts for 2.2% of the variance in grief intensity, in support of an overall significantly predictive linear model. The relationship between duration of illness and grief intensity is apparently linear, rather than nonlinear, as first hypothesized.

It was also hypothesized that the variables of sex of parent and sex of child would act as moderators between the effect of time since diagnosis and grief intensity. The results of ANOVA analyses indicated that sex of parent and sex of child do not have a significant effect on the intensity of grief, however. It should be noted that dividing the

sample to investigate the impact of parent sex, child sex, and duration of illness resulted in very unequal group sizes, which in some cases resulted in very small groups. This may have had an effect on the significance level of the analysis.

Finally, feelings of vocational lost potential were anticipated to moderate grief intensity. It was anticipated that parents who endorsed a higher level of vocational lost potential would also endorse experiencing a higher level of grief intensity. The results failed to significantly support this hypothesis, however. In addition, the interaction of vocational lost potential, parent sex, and child sex was not significant. It should be noted that the ANOVA analysis conducted was hampered by unequal sample groups; higher participation by fathers was sought, but they remained a minority of the participants.

There were a few unanticipated significant pairwise relationships among variables in the present study. The current age of the child was significantly negatively correlated with the intensity of the parent's grief, suggesting that grief is higher when the child is younger. The effect of the parent's age was close to significant and was also negatively correlated with the intensity of grief. Both of these relationships have the passage of time in common. Correlation analyses revealed that child's age and duration are significantly positively correlated in the multiple regression ($r = .220, p=.033$). Parent's age and duration are also positively correlated, but it is not quite significant ($r=.181, p=.065$). These results may suggest the presence of a more temporal process, which would be appropriate for a follow-up longitudinal study.

The results of a multiple regression analysis suggested that the child's current age is the most important predictor of grief intensity. Specifically, the child's current age was negatively related to parental grief and accounted for 7.7% of the variance in grief

intensity. The duration of the illness was also negatively related to parental grief intensity, but accounted for only 2.2% of the variance. The parent's age had a negligible impact. In addition, the child's current age made the strongest unique contribution to explaining the intensity of grief when the variance explained by the other variables (duration of illness, parent sex, child sex, vocational lost potential, and parent age) was controlled. This unique contribution was found to be statistically significant in the prediction of grief intensity. This significant negative relationship between the child's current age and grief intensity suggests that grief is actually higher when the child is younger. A possible explanation for this result could be related to the normal expectations that parents have for their children. There are many developmental milestones that are expected to occur in a child's life, such as graduating from high school and college, having a successful career, getting married, and having children. The earlier mental illness strikes, the fewer of these milestones the child may be able to achieve. An alternative explanation could be related to the existence of hope for improvement, in other words, the younger the adult child, the more hope there still is for improvement. These feelings of hope could obstruct the parents' ability to accept the child's illness and adapt to it.

The negative relationship between duration of illness and intensity of grief indicates that grief mainly decreases as the time since diagnosis increases. This may occur because the parent becomes more able to accept the illness and find ways to cope with its consequences. Since the study participants were members of NAMI and the majority of their children had been ill for over six years, support group membership could

also be a factor in the reduction of this grief. More research is needed to understand this change over time.

The emergence of the negative relationship between grief intensity and child's age, as well as duration of illness, demonstrates the need for early therapeutic intervention with parents to help them cope with the child's illness in the healthiest manner possible. This, in turn, would likely increase the child's ability to cope with the illness.

Strengths

Although the MIV-TIG measure has been used before (Miller et al., 1990), this particular study has not been previously conducted, to my knowledge. In addition, the assessment of lost potential has only been done on patients, rather than parents, in the past (Lewine, 2004).

Based on the sample sizes of other studies in this area of research, difficulty recruiting a large sample is common. Of the fifteen other studies identified in this area, only two have a larger sample size. Of those two, only one contained at least 159 participants. That study was a large national study. Ten of the fifteen studies had fewer than thirty participants; five had fewer than ten. Compared to the current literature, this study's sample of 78 is fairly sizable.

Limitations

There are significant limitations to consider in this study. The participants were mostly Non-Hispanic White members of a support and advocacy group for mental illness, so they may not be representative of the population of parents as a whole. They could be viewed as self-selected participants by virtue of their involvement in a support group.

Unfortunately, NAMI family support group meetings were not well attended by members of minority groups or by fathers. In addition, it should be assumed that parents in this study were in distress over their child's mental illness, since they experienced the need for a support group.

Another consideration in this study is that information was obtained through the use of self-report measures (sociodemographic form, lost potential survey, parental burden survey, and MIV-TIG), which are subjective in nature. In addition, the retrospective nature of the measures relies heavily on the memory of the parent for emotions and thoughts experienced in past years, which may not be accurate. These measures were quantitatively based, however, as opposed to the narrative interviews used in other studies.

In hindsight, the use of a continuous scale for the retrospective report of grief on the MIV-TIG would have lent more precision and utility than is probably the case. Finally, the low percentage of participation by fathers led to unequal and very small group sizes in some ANOVA analyses, violating the assumption of homogenous variances.

Implications

Overall, the results of this study provided a variety of interesting information. Grief intensity was shown to be highest for illness durations from 4 to 6 years and lowest for illness durations greater than six years. The sex of the parent and the sex of the child did not have a significant impact on grief intensity, according to the results of an analysis of variance. Controlling for caregiver burden did not significantly affect the results.

Analyses of mean grief intensity scores based on level of vocational lost potential indicated no significant relationship exists between the two variables.

The best predictor of grief intensity was actually found to be the current age of the child. This significant, negative relationship suggests that grief is higher the younger the child. Parents may be grieving the loss of developmental milestones their child will not reach. Another view is that the younger the adult child, the more hope there still is for improvement. These feelings of hope could obstruct the parents' ability to accept the child's illness and adapt to it.

The implications of this study are important, since the results inform clinicians' treatment of grief experienced by the parents of adult children with an SMI. The results also inform clinicians as to the possible time course of grief and the need for earlier intervention to help parents anticipate and cope with the impact of the child's illness after a diagnosis is determined. Since parental grief appears to be higher at illness durations from 4 to 6 years, it is important that clinicians do not stop assessing grief too early.

The early years after a diagnosis is obtained appear to be the most stressful, as parents have to learn what the diagnosis means for the family and the child. The full impact of the illness takes time to understand, making it difficult for families to plan for future resources and challenges. This creates an interesting discontinuity - stress is predominant early in the adjustment process, while grief occurs later. This is why clinicians should not confuse the two.

It has been reported in the literature reviewed that the parents of children with a severe mental illness suffer from chronic grief that may be unrecognized and untreated (MacGregor, 1994; Miller et al., 1990; Pejler, 2001; Tuck et al., 1997; Karp &

Tanarugsachock, 2000; Miller, 1996; Jungbauer, 2004; Atkinson, 1994). This grief is unlike depression, which is a serious mental illness that can occur under the best of circumstances and requires treatment. The parents' grief may be delayed because of a lack of a diagnosis, the inability to accept a diagnosis, or the assumption that the children are simply experiencing a difficult adolescence. The chronic and delayed nature of the parents' grief is reflected in the duration of their grief, as they continue to hold onto the hope that their children will recover.

Sex differences in the parents and the children, as well as the interaction of these sex differences, was anticipated to play a role in the intensity of grief experienced by the parents, but this study did not support that expectation. A study with greater participation by fathers would be required to investigate this more fully. In addition, vocational lost potential was found to have an insignificant effect on grief intensity.

These factors could be important in understanding the parents' grief and helping them to heal and cope earlier in the process. The mental health of the parents should be supported so that they, in turn, can better support the mental health of the ill child. Collaboratively including parents and family members in the treatment of the ill family member can increase mental health providers' knowledge and the adherence of the family member to treatment goals (Chen & Lukens, 2011). In addition, treatment providers and researchers have not thoroughly addressed the therapeutic needs of the parents as yet. Current grief therapies may need to be adapted to serve this population. In other words, parents may need intervention in their own right due to the many consequences of the adult child's illness.

Due to inconsistent findings in this area of research (Richardson & Murray, 2011), more studies need to be conducted to determine useful predictors of the presence and intensity of grief in parents, as well as the impact demographic and socioeconomic variables may have.

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APPENDIX

Sociodemographic form (circle correct answer)

1. Parent's Sex M F
2. Parent's Race W B H A Other _____
3. Parent's Years of education 0-8 9-12 GED 13+
4. Parent's Age <30 30-49 50-64 65+
5. Parent's Marital status Single Married Divorced Widowed Separated
6. If parent is single: Single Head of Household Supported by others
7. If parents are divorced, how long: <1 year 1-3 4-6 7+ years
8. Both child's parents alive? Yes No
9. Child's sex M F
10. Child's race W B H A Other _____
11. Child's years of education 0-8 9-12 GED 13+
12. Child's age <30 30-49 50-64 65+
13. Child's diagnosis: Schizophrenia Bipolar Disorder Other _____
14. Child on medication? Y N If yes, name _____
15. Duration of child's illness (years), based on 1st hospitalization or when first psychiatric diagnosis received < 1 year 1 2 3 4 5 6 > 6 yrs
16. Does the child see a therapist? Y N How often? weekly monthly
17. Is child employed? Y N If so: full-time half-time part-time other _____
18. If child has worked, duration of longest employment: <1 year 1-3 >3 years
19. If child has worked, type of employment: Unskilled Skilled Professional
20. Is the child adopted or biological? Adopted Biological
21. If adopted, what was the child's age at adoption? <1 year 1-5 6-10 11+

LOST POTENTIAL

Date: _____

I am: mother___ father__ guardian___

Child sex: _____

Child Age: _____

Mother's education: _____

Mother's job: _____

Father's education: _____

Father's job: _____

LOST POTENTIAL

Introduction

People caring for children with emotional or mental difficulties often find that they are unable to pursue some of the plans they had before the onset of their problems. Sometimes there are specific goals or expectations they had that the child's disorder prevents them from meeting. The following questions are intended to gain a better understanding of what you believe you've lost because of the disorder your child has. There are no right or wrong answers as the focus is on your experience.

Questions

1. When did you first begin to realize that things were not going as you had expected in your child's life? What led you to this conclusion?

2. What has your child been prevented from accomplishing because of his/her _____ [disorder]? [For example, in education, work, or interpersonal areas]

3. What did you expect your child to be doing at this time in his/her life before the development of problems with _____ [disorder]? [For example, in education, work, or interpersonal areas]

1. What job or type of job did you expect your child to have by now (before the illness)?

2. What job or type of job does your child currently have? If not working, use 'unemployed'.

4A. Of the different "losses" you've described, which has been the most disappointing or frustrating? What is it about not being able to _____ [loss of potential] that is disappointing or frustrating?

4B. Please rate the level of your disappointment (circle one):

1 = none; 2 = minimal; 3 = somewhat; 4 = moderate; 5 = intense

4C. To whom have you talked about these disappointments? Would you like to talk about [lost potential] if you had the chance?

5. How have you tried to cope with your disappointment? What doesn't work? What works best?

What advice would you give someone who is caring for a child with the same disorder?

MENTAL ILLNESS VERSION OF THE TEXAS INVENTORY OF GRIEF¹

(circle the best response)

Completely False	Mostly False	Neither True nor False	Mostly True	Completely True
1	2	3	4	5

Part 1 (past behaviors)

1. I found it hard to get along with certain people.

1 2 3 4 5

2. I found it hard to work well when I became aware of his/her mental illness.

1 2 3 4 5

3. I lost interest in other family members, friends, and relatives.

1 2 3 4 5

4. I found a need to do things the way he/she used to do them.

1 2 3 4 5

5. I was unusually irritable.

1 2 3 4 5

6. I couldn't keep up with my usual activities for the first three months.

1 2 3 4 5

7. I was angry with him/her for the changes that were taking place.

1 2 3 4 5

8. I found it hard to sleep.

1 2 3 4 5

¹ Miller, F., Dworkin, J., Ward, M., & Barone, D. (1990). A preliminary study of unresolved grief in families of seriously mentally ill patients. *Hospital and Community Psychiatry, 41*(12), 1321-1325.

Mental Illness Version of the Texas Inventory of Grief¹

(circle the best response)

Completely False	Mostly False	Neither True nor False	Mostly True	Completely True
1	2	3	4	5

Part 2 (present feelings)

9. I cry when I think about how he/she used to be before the illness.

1 2 3 4 5

10. I cry when I think about how he/she could have been if not for the illness. *

1 2 3 4 5

11. I get upset when I think about how he/she used to be before the illness.

1 2 3 4 5

12. I get upset when I think about how he/she could have been if not for the illness. *

1 2 3 4 5

13. I very much miss the way he/she used to be.

1 2 3 4 5

14. It is painful to recall memories of how he/she used to be.

1 2 3 4 5

15. I am preoccupied with thoughts about how he/she used to be before the illness.

1 2 3 4 5

16. I am preoccupied with thoughts about how he/she could have been if not for the illness. *

1 2 3 4 5

17. I hide tears when I think about him/her.

1 2 3 4 5

¹ Miller, F., Dworkin, J., Ward, M., & Barone, D. (1990). A preliminary study of unresolved grief in families of seriously mentally ill patients. *Hospital and Community Psychiatry, 41*(12), 1321-1325.

Mental Illness Version of the Texas Inventory of Grief¹

(circle the best response)

Completely False	Mostly False	Neither True nor False	Mostly True	Completely True
1	2	3	4	5

18. No one will ever take the place that he/she used to have in my life.

1 2 3 4 5

19. I can't avoid thinking about how he/she was before the illness.

1 2 3 4 5

20. I can't avoid thinking about how he/she could have been if not for the illness. *

1 2 3 4 5

21. I feel it is unfair that he/she became mentally ill.

1 2 3 4 5

22. Things and people around me still remind me of the way he/she used to be.

1 2 3 4 5

23. I cannot accept his/her mental illness.

1 2 3 4 5

24. At times I still feel the need to cry for him/her.

1 2 3 4 5

25. Please think back to when your child's first serious problems began. Please rate the intensity of your grief for each of the following time periods after realizing that your child was ill. Use a scale of 1 (no or low grief) to 5 (very intense grief) to rate each time period.

Time periods

0 to 3 years	1	2	3	4	5
4 to 6 years	1	2	3	4	5
>6 years	1	2	3	4	5

¹ Miller, F., Dworkin, J., Ward, M., & Barone, D. (1990). A preliminary study of unresolved grief in families of seriously mentally ill patients. *Hospital and Community Psychiatry, 41(12)*, 1321-1325.

26. Now think back to when you received the first psychiatric diagnosis for your child. Rate the intensity of your grief for each of the following time periods after receiving the diagnosis. Use a scale of 1 (no or low grief) to 5 (very intense grief).

Time periods	1	2	3	4	5
0 to 3 years					
4 to 6 years					
>6 years					

* Items expected to be related to lost potential.

THRESHOLDS PARENTAL BURDEN SCALE (TPBS)

J. A. Cook & S. A. Pickett

Instructions: We are interested in your feelings and experiences in helping your child to cope with his or her problems. For each statement, please circle the letter that best describes how you feel.

- | Strongly agree
(a) | Moderately agree
(b) | Slightly agree
(c) | Slightly disagree
(d) | Moderately disagree
(e) | Strongly disagree
(f) |
|--|-------------------------|-----------------------|--------------------------|----------------------------|--------------------------|
| 1. I will always be prepared to take financial responsibility for _____. | | | | | a b c d e f |
| 2. One of the hardest things about dealing with _____ is that his or her problems are so unpredictable. | | | | | a b c d e f |
| 3. _____ needs me much more than any of my other family members. | | | | | a b c d e f |
| 4. I worry about what the future will bring for _____. | | | | | a b c d e f |
| 5. Sometimes, I feel that my life and _____'s life are inseparable. | | | | | a b c d e f |
| 6. Sometimes, I feel that _____ is not really troubled but instead is just being lazy or uncooperative. | | | | | a b c d e f |
| 7. Sometimes, I find it hard to stop thinking about _____ and his/her problems. | | | | | a b c d e f |
| 8. I feel that _____ tries to manipulate me. | | | | | a b c d e f |
| 9. If I don't help _____, no one else will. | | | | | a b c d e f |
| 10. I wish _____ would show better grooming and personal hygiene. | | | | | a b c d e f |
| 11. I can't imagine life without _____. | | | | | a b c d e f |
| 12. I often feel mixed up about how much I should be doing for _____. | | | | | a b c d e f |
| 13. I continue to hope that _____ will be like his or her old self again. | | | | | a b c d e f |
| 14. Of all my family, I feel the most closely connected to _____. | | | | | a b c d e f |
| 15. I feel embarrassed over the behavior of _____. | | | | | a b c d e f |
| 16. Because I spend so much time helping _____, this causes hardships for my other children. | | | | | a b c d e f |
| 17. No matter how hard it is to control his or her behavior, _____ will always be welcome in my home. | | | | | a b c d e f |
| 18. My family and I often have disagreements about my involvement with _____. | | | | | a b c d e f |
| 19. Sometimes, trying to deal with _____'s problems makes me feel helpless. | | | | | a b c d e f |
| 20. Nobody understands _____ as well as I do. | | | | | a b c d e f |
| 21. I feel useful when I help _____. | | | | | a b c d e f |
| 22. I feel that I'm more committed to _____ than to my spouse. | | | | | a b c d e f |
| 23. I can never plan to do things with other people unless I first stop and think about whether or not _____ will need me. | | | | | a b c d e f |
| 24. Sometimes, I'm not sure where _____ fits in as part of the family. | | | | | a b c d e f |

25. I would sacrifice my life to save _____ . a b c d e f
26. One of the hardest things about _____ 's problem is worrying about whether or not the worst symptoms will occur again. a b c d e f
27. No matter what else happens in _____ 's life, I know that I will always be responsible for him/her. a b c d e f
28. I'm not sure how much I should expect _____ to help around the house. a b c d e f
29. I feel that _____ is too dependent on me. a b c d e f

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Scoring instructions: Responses are scored a = 6, b = 5, c = 4, d = 3, e = 2, and f = 1. Responses to all 29 items are summed to obtain a total burden score, with higher scores indicating high levels of burden. Response values within each subscale may also be added to arrive at subscale scores. Subscales and their constituent items are feelings of ongoing connection to the ill offspring and his/her needs (3, 5, 9, 14, 20, 22), mental preoccupation and constant worry about the ill offspring (7, 11, 23, 25), perceptions of ongoing and ultimate responsibility for the ill offspring's well-being (1, 17, 27), inability to manage the ill offspring's behavior (8, 12, 16, 19, 29), family disagreement regarding the ill offspring (10, 15, 18, 24), and concerns regarding reoccurrence of psychiatric symptoms and the ill offspring's future.

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CURRICULUM VITAE

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Educational Background

- December 2009 Passed the EPPP licensing exam in Kentucky at the doctoral level. Licensed as a Psychological Associate in Kentucky prior to internship.
- 2005 – present Ph.D. Program in Clinical Psychology, University of Louisville
Mentor: Richard Lewine, Ph.D.
Dissertation title: “Grief and Lost Potential in the Parents of Adult Children with Severe Mental Illness”
Dissertation defense: July 2, 2012
- 2005 – 2007 M.A., Clinical Psychology, University of Louisville
Mentor: Richard Lewine, Ph.D.
- 2005 B.A., Psychology, University of Louisville

Clinical Experience

Clinical employment:

- 07/11 – 06/12 Central Iowa Veterans Administration Hospital, Des Moines, IA:
Internship training and supervision. Completed PTSD Residential and Outpatient rotation. Conduct outpatient therapy using Prolonged Exposure and Cognitive Processing Therapy; completed training for CPT and began supervision to become certified in CPT during internship year. Have conducted therapeutic and psychoeducational groups in PTSD residential program, PTSD outpatient program, Acute psychiatric unit, and Community Living Center chronic psychiatric unit. Conducted regular assessments for Traumatic Brain Injury, PTSD, and other psychological disorders. Assisted psychologist in CLC with implementation of a behavioral management program. Serve on Disruptive Behavior Committee. Have utilized ACT, CBT, PE, CPT, and Mindfulness interventions in therapy.
Supervisors: John Wallace, Ph.D., Director, Psychology Training
John Junginger, Ph.D., Psychology Executive
Steve Hagemoser, Ph.D., PTSD program

Paul Essen, Psy. D., TBI program

- 03/10 – 06/11 Dr. David Wunsch & Associates, Louisville, KY: Conducted a variety of psychological assessments on adults and children as a Licensed Psychological Associate. Assessments included intelligence, personality, substance abuse, severe mental illness, disability, developmental delay, and parenting behavior. Supervisor: David Wunsch, Ph.D.
- 07/10 – 06/11 Veterans Administration Hospital, Louisville, KY. One-year practicum for one day per week. Assigned to substance abuse residential rehabilitation unit (SARRTP). Responsibilities included individual therapy and group therapy using 'fish bowl' process group and Relapse Prevention Therapy. Supervisor: Stephen Bliss, Psy. D.
- 07/07 – 06/08 Central State Hospital, Louisville, KY. One-year placement for 20 hours per week. Rotated through three adult units for acute mental illness. Conducted initial assessments, risk assessments, intelligence assessments, personality assessments, malingering assessments, individual therapy, and psychoeducational group therapy. Involved as member of multi-disciplinary treatment team. Supervisors: Nancy Schrepf, Psy. D. and Wayne Putnam, Ph. D.
- 07/06 – 06/07 Noble Kelley Psychological Services Center, University of Louisville. One-year placement as a Clinic Assistant for 20 hours per week. Conducted brief phone interviews with prospective clients to determine applicability for therapy or assessment at the center. Performed in-person intake interviews with prospective therapy clients. Greeted clients and collected payments from them. Instructed first-year graduate students in WAIS-III and WISC-IV assessments and in proper interviewing skills. Supervisor: Bernadette Walter, Ph. D.
- Clinical teams:
2007 – 2009 Mindfulness clinical team: health-focused clinical team using mindfulness interventions to increase health, lower stress, and decrease pain. Clients experienced a wide variety of medical and psychological issues. Mentor: Paul Salmon, Ph.D.
- 2005 – 2007 Psychopathology clinical team: focused on severe mental illness symptoms and treatments to enhance ability of clients to live productively in the community. Clients experienced severe mental illnesses such as bipolar disorder, depression, and mild psychosis.

Conducted psychoeducational weekly group therapy sessions at the University of Louisville Hospital Psychiatric unit.
Mentor: Richard Lewine, Ph.D.

Research Experience

2005 to present Psychopathology graduate research lab
Mentor: Richard Lewine, Ph.D.

Dissertation study: “Grief and Lost Potential in the Parents of Adult Children with Severe Mental Illness”.
Preliminary examination paper: “Comparison of grief symptoms between parents of children with a severe mental illness and parents of deceased children”.

Researched factors that are correlated with suicidal ideation in psychosis.

Studied the effects of mild depression on neurocognitive functioning in college freshmen.

2004 – 2005 Undergraduate research lab, Dr. Lewine.
Performed neuropsychological tests on Psychology 201 student research volunteers.

Researched literature regarding schizophrenia co-morbid with depression and suicidal ideation.

Researched current treatments for depression related to schizophrenia.

Researched depression, suicide screening, and suicide in college students.

Publications and Presentations

2010 Eisenmenger, K. Grief and Lost Potential in the Parents of Adult Children with Severe Mental Illness. Presented to Lexington, KY chapter of National Alliance on Mental Illness (NAMI).

2009 Eisenmenger, K. Grief and Lost Potential in the Parents of Adult Children with Severe Mental Illness. Presented to Psychology department graduate students.

- 2007 Eisenmenger, K., Lewine, R., & Shriner, B. Factors Correlated with Suicidal Ideation in Psychosis. Presented at the 2007 SRP (Society for Research in Psychopathology) conference.
- 2006 Eisenmenger, K. & Lewine, R. Mild Depression and Neurocognitive Functioning in College Freshmen – Updated. Presented at the 2006 SRP (Society for Research in Psychopathology) conference.
- 2005 Eisenmenger, K. & Lewine, R. Mild Depression and Neurocognitive Functioning in College Freshmen. Presented at the 2005 KPA (Kentucky Psychological Assoc.) and 2005 SRP (Society for Research in Psychopathology) conferences.
- 2004 Eisenmenger, K. Depression and Suicide Screening on Campus.

Colloquia and Seminars Attended

- 2009 – 2010 Depression Center Professional Conference; Drs. Judith Beck, Allan Tasman, Paul Keck, Jr., David Casey, Jesse Wright; “Searching for Solutions: Advances in the Treatment of Mood Disorders”
Kentucky Psychological Association Annual Convention Seminars, “Dementia” and “Post-traumatic Stress Disorder”
Dr. Kenneth Furman, Major, USAF, “Air Force Suicide Prevention Program: A Model for Community and Organizational Approaches to Prevention”
- 2008 – 2009 Grawemeyer talk, Dr. Elizabeth Loftus, “Rich False Memories”
Grawemeyer talk, Dr. Albright, “In your mind’s eye: Common neural substrates for seeing and remembering”
Dr. Purvis, “The Impact of Internalized Homophobia on Gay and Lesbian Psychological Development”
Public talk, Elyn Saks, author of “The Center Cannot Hold”
Workshop, Dr. Eells, “Psychotherapy Case Conceptualization”
Workshop, Dr. Maccow, “WAIS-IV training”
Dr. Lewine & Dr. Lyle, “Evidence-Based Teaching”
- 2007 – 2008 Society for Research in Psychopathology Conference, Iowa City, Iowa
Kentucky Psychological Association Seminar, “Complex PTSD”
Dr. Albert Bandura, Grawemeyer Award winner, Department talk
Dr. Inka Weissbecker, “The Role of Psychologists at the United Nations: Global Partnerships and Service Learning”
Dr. Paul Kieffaber, “Mechanisms of Cognitive Control, Context Processing, and Cognitive Deficits in Schizophrenia”
Dr. Lisa Emery, “Affect-Cognition Relationships in Older Adults”

Dr. Wen Li, "Thinking by the Heart and the Mind: Explorations of Cognition-Emotion Interactions"

2006 – 2007 Society for Research in Psychopathology Conference, San Diego, CA
Seminar, Dr. Jesse Wright, "CBT for Severe Mental Illness"
Seminar, Kentucky Psychological Association, "DBT training"

Professional Memberships

American Psychological Association
Kentucky Psychological Association
Society for Research in Psychopathology
National Alliance on Mental Illness (NAMI-KY)

References (Letters of recommendation available upon request)

Dr. John Wallace
Licensed Clinical Psychologist
Director of Psychology Training
PTSD Program Coordinator
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Des Moines, IA 50310
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PTSD Program
VA Central Iowa Health Care System
3600 30th Street
Des Moines, IA 50310
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Email: Steven.Hagemoser2@va.gov

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