COPING WITH THE PERSONAL LOSS OF HAVING A PARENT WITH MENTAL ILLNESS: YOUNG ADULTS’ NARRATIVE ACCOUNTS OF SPIRITUAL STRUGGLE AND STRENGTH

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ABSTRACT

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Children who have parents with mental illness are typically considered “at-risk” for a variety of conditions, such as increased psychopathology and lower self-esteem. Research generally examines children and adolescents who have parents with mental illness and often relies on parents and professionals as data sources. Yet, relatively little is known about the experiences of young adults coping with parents with mental illness from their own perspective, especially as it relates to their experience of personal loss due to their parents’ mental illness, their religious experiences, and the meaning they ascribe to their experience.

The present qualitative research examined the narratives of nine young adults coping with parents with mental illness, focusing specifically on their experiences of personal loss due to their parents’ mental illness, their faith journeys and associated spiritual struggles, and the perceived impact of coping with a parent with mental illness. Results suggest that individuals who are experiencing personal loss in their lives to a greater extent also feel more confused on their faith journey, experience more spiritual struggle, and feel more negatively impacted as a result of their parents’ mental illness. Participants feeling less personal loss in their lives, on the other hand, tended to feel more content on their faith journey, experience less spiritual struggle, and feel more positively impacted by their parents’ mental illness. However, all participants described various strengths associated with their life circumstance, such as feeling independent, strong, and compassionate. Implications for the use of qualitative research among marginalized groups are discussed, as well as directions for future research.
For Chris
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INTRODUCTION

The study of children coping with parents with mental illness has been a focus of much research over the past several decades (Jacob & Johnson, 1997; Kauffman, Grunebaum, Cohler, & Gamer, 1979; Mowbray, Bybee, Oyserman, MacFarlane, & Bowersox, 2006). Researchers have typically conceptualized this population as “at-risk” for a number of conditions such as increased psychopathology (Biederman et al., 2001), lower self-esteem (Williams & Corrigan, 1997) and academic problems (Mowbray, Bybee, Oyserman, MacFarlane, & Bowersox, 2006). Studies have often used the perspectives of parents or mental health professionals to examine the individual deficits and associated risks of being a child/adolescent of a parent with mental illness (Biederman et al., 2001; Jacob & Johnson, 1997, for example). Yet, relatively little is known about the experiences of young adults as they cope with the experience of mental illness in their families.

Previous research has highlighted the importance of religion for young adults coping with difficult life circumstances (Pargament, Koenig, & Perez, 2000) and feelings of personal loss due to mental illness experienced by family members (Stein & Wemmerus, 2001). The present qualitative study examines the first person accounts of nine young adults attending a Midwestern university to better understand the role of personal loss due to mental illness, spiritual struggle, and perceived personal consequences of having a parent with mental illness. The goals of the research are to examine first hand accounts of the experiences of young adults coping with a parent with mental illness, focusing specifically on the relationship between personal loss due to mental illness and reports of participants’ faith journeys, spiritual struggles, and perceived impact of having a parent with mental illness. The study purposefully focuses on the personal accounts of young adults to describe their views and to give voice to their experiences.
Children of Parents with Mental Illness

Research suggests that children of parents with mental illness are at an increased risk of mental illness themselves (Williams & Corrigan, 1992), have a decreased self-esteem (Williams & Corrigan, 1992), have increased attentional problems (Grunbaum & Kohler, 1982), suffer from inadequate social adjustment (Jacob & Windle, 2000), have decreased social functioning and social support (Biederman et al., 2001; Stromwall & Robinson, 1998), and are at increased risk for social avoidance (Williams & Corrigan, 1992). Having a parent with mental illness has also been associated with marital, educational, and occupational problems (Stromwall & Robinson, 1998; Weissman, et al., 1997). It is important to briefly review the underlying assumptions, methods, and major findings of research documenting the at-risk status of children of parents with mental illness.

The Perspectives of Parents Professionals

The majority of studies assessing psychopathology and psychosocial functioning in offspring coping with a parent with mental illness use a mix of methodological designs and use the perspectives of parents and professionals as the focus of inquiry (Biederman et al, 2001; Pilowsky et al., 2006). Moreover, the large majority of studies using these perspectives focus on children and adolescents. Results from these studies usually report deficits and risks associated with having a parent with mental illness.

Biederman et al. (2001), for example, was interested in the psychosocial outcomes of 380 children/adolescents of mothers with panic disorder and/or major depressive disorder. Psychopathology and global functioning was assessed via clinical interview, and behavioral dysfunction was assessed with a behavior checklist completed by the mother. Results indicated that, compared to the control group, children of parents with panic disorder and/or major
depressive disorder had significantly higher rates of anxiety disorders and depression. Additionally, children in these groups scored significantly higher in several problem behavior areas, including somatic problems, withdrawal, aggression, and destructive behaviors, and scored lower in social and school functioning.

In another study, Pilowsky et al. (2006) assessed the psychosocial outcomes for children/adolescents (ages 7-17) of mother’s currently experiencing a major depressive episode. Clinicians rated psychopathology and global functioning, and parents rated behavioral functioning. Results indicated that children of mothers with a comorbidity of depression and panic disorder were eight times as likely to have depression, even after controlling for the child’s age and gender and the mother’s severity of depression. In addition to this increased likelihood, maternal substance abuse disorder and a history of suicide attempts were significantly associated with a three-fold increase in children’s depression.

Some research has assessed the relationship between child psychosocial functioning and the father’s mental illness. Jacob and Johnson (1997), for example, used a sample of children/adolescents of mothers with depression and a sample of children/adolescents of fathers with depression. Mothers and fathers filled out an adjustment and behavior checklists. Overall, results indicated that children/adolescents in families with depression had significantly higher rates of depression, behavior problems, and internalizing and externalizing behaviors as compared to control families.

These studies provide an illustration of the assumptions, methods, and major findings of the research using parental and professional perspectives of the outcomes associated with having a parent with mental illness. These quantitative studies assume that children/adolescents are at risk by virtue of having a parent with mental illness. Other aspects of these children/adolescents
experiences are not taken into consideration when presented in this way, and results do, indeed, indicate that this population is at risk for a number of psychological, social, behavioral, and educational problems.

The Perspectives of Young Adults

Some research, however, has assessed psychosocial outcomes from the perspective of offspring coping with parents with mental illness, mainly young adults. Of this scant research, some studies have used quantitative methods. Williams and Corrigan (1997), for example, assessed various psychosocial outcomes, such as self-esteem, anxiety, and social support for 139 young adults of parents with mental illness, alcohol abuse, and substance abuse. Results indicated that young adults of parents with mental illness were more socially anxious and had lower self-esteem than controls. Additionally, young adults of parents with mental illness scored lower on depression and higher on trait anxiety when compared to young adults of parents with alcohol-abuse and controls.

Of the research that assesses outcomes of these young adults, few studies use qualitative methods to describe young adults’ experiences. In one of the only studies found, Kinsella & Anderson (1996) were interested in using qualitative interviews to explore areas such as coping skills, needs, and perceived strengths for 10 young adults of parents with mental illness. Results indicated that all participants reported experiencing positive growth from their circumstances. Specifically, participants reported feeling independent/self-reliant, empathic/tolerant, resilient, assertive, resourceful/creative, and having developed a broader spiritual perspective. Although researchers did not ask participants to describe their perceived limitations as a result of coping with a parent with mental illness, this research emphasizes the positive growth that participants report when given the opportunity to do so qualitatively.
These studies provide a sample of the scant research on young adults’ perspectives of the consequences of coping with a parent with mental illness. When assessed quantitatively, results indicate that this population is at risk for a variety of negative psychosocial outcomes. However, when given the opportunity to voice their experiences through qualitative research, young adults discuss positive aspects of growth that are related to their circumstances.

**Limitations to the Current Research on Children of Parents with Mental Illness**

Although previous research highlights some important findings for children of parents with mental illness, there are also several limitations to this research. First, the literature predominantly focuses on children and adolescents between the ages of 4-18 years (Biederman et al., 2001; Pilowsky et al., 2006). Of the research on children and adolescents, a majority of the studies rely heavily on reports from parents and professionals, using quantitative methods (Biederman et al., 2001; Jacob & Johnson, 1997; Pilowsky et al., 2006). As such, this research tends to highlight the deficits and risks associated with coping with a parent with mental illness.

Some research, however, has assessed psychosocial outcomes from the perspectives of the offspring, mainly young adults coping with a parent with mental illness (Williams & Corrigan, 1997; Kinsella & Anderson, 1996). When quantitative methods are used (Williams & Corrigan, 1997), there is a focus on negative outcomes, similar to quantitative reports from parents and professionals. However, when qualitative methods are used (Kinsella & Anderson, 1996), and young adults are provided with the opportunity to voice their experiences, this population shares a number of positive aspects that they perceive as being directly related to their life circumstances. More qualitative research is needed to provide insight into the lived experiences of this population. The next section focuses on another experience among people
affected by mental illness that has benefited from the use of qualitative research – personal loss due to mental illness.

Personal Loss due to Mental Illness

The study of personal loss due to mental illness has received increasing attention among researchers in recent years (Ryan, 1993; Stein, 2005; Stein, Dworsky, Phillips, & Hunt, 2005). Personal loss due to mental illness includes the “subjective experience of loss due to psychiatric disability and psychosocial losses due to changes in functioning and a lack of access to valued social roles” (MacGregor, 1994; Stein, 2005; Stein, Dworsky, Phillips, & Hunt, 2005). Personal loss has been studied within the context of families with an ill member (Stein & Wemmerus, 2001) and among people diagnosed with serious mental illness themselves (Stein, 2005; Stein, Dworsky, Phillips, & Hunt, 2005). Although conceptualized as a distinct phenomenon, research on personal loss due to mental illness is grounded in an extensive literature on loss and grief, such as loss due to divorce (Harvey, 2002), loss due to death (Stroebe & Schut, 2001), and grief due to having a child diagnosed with mental illness (Davis & Schultz, 1998).

In order to provide a context for research on personal loss, it is important to briefly review the study of grief related to having a child with mental illness, noting assumptions and basic findings. Researchers interested in the grief associated with coping with a child with mental illness theorize that this grief is distinct from other types of grief. For example, MacGregor (1994) notes that the diagnosis of mental illness is the start of multiple future losses for both the parents and the child, and that dealing with this grief is often compounded by a lack of recognition within society of its existence or significance. Not surprisingly, research indicates that parents of children with schizophrenia do, in fact, experience grief as it relates to their child’s psychiatric disability (Davis & Schultz, 1998). Additionally, greater grief has been
associated with greater objective and subjective burden in families coping with a member with serious mental illness (Solomon & Draine, 1996). This research was instrumental in establishing grief related to a child’s mental illness as a distinct and significant phenomenon from other types of grief, while also providing direction for future research on personal loss due to mental illness.

The experience of personal loss due to mental illness includes feelings of loss due to the personal and social changes that often accompany the diagnosis of psychiatric disability (MacGregor, 1994; Stein, 2005; Stein, Dworsky, Phillips, & Hunt, 2005). Indeed, initial qualitative research studies have indicated that family members and people themselves diagnosed with schizophrenia report experiencing various losses, including the loss of a normal life, loss of a loved one, and loss of freedom (Ryan, 1993; Stein & Wemmerus, 2001).

In one qualitative study, Ryan (1993) was interested in the experiences of five mothers with adult children with schizophrenia. This research used an ethnographic approach in order to gain a better understanding of their experiences from the mothers’ point of view. Results indicated that mothers experience as sense of disruption and loss as a result of caring for their adult children. Specifically, mothers reported experiencing a loss of their child’s potential to lead a normal life and a loss of freedom in the mother’s life.

In another qualitative study, Stein and Wemmerus (2001) interviewed 22 family members (adults with schizophrenia, parents, and well-siblings) about the impact of schizophrenia on family life. Results indicated that distress was a common experience felt by all of the families, especially as it relates to the personal and social changes associated with the family member’s diagnosis of schizophrenia. Specifically, adults with schizophrenia reported experiencing a loss of a normal life, which included the loss of skills and abilities, a loss of personal relationships,
the loss of prized possessions, and the loss of a place in society. Parents also reported experiencing loss, especially as it relates to the loss of their child’s abilities and potential.

From this qualitative study, Stein and colleagues (2005) developed a measure of personal loss among adults coping with serious mental illness. Using a sample of 158 adults with psychiatric disability, these researchers examined the psychometric properties of the Personal Loss from Mental Illness Scale. Results suggest four different types of loss: loss of roles and routine, loss of former relationships, loss of former self, and loss of future. Results indicate that the experience of personal loss due to mental illness was associated with greater loneliness, more severe and distressing psychological symptoms, more problem drinking, and less positive well-being for young adults who have been diagnosed with mental illness.

Stein (2005) was also interested in personal loss and other associations with various life aspirations. Specifically, Stein examined personal loss due to mental illness and its association with aspirations, ability, and support to attend college. Using a sample of 80 adults with psychiatric disability, researchers found that various elements of personal loss were associated with fewer aspirations and plans to attend college and with self-perceptions of less intellectual and emotional capacity for college. Interestingly, overall illness severity was not associated with assessments of capacity or plans for college, suggesting that personal loss due to mental illness played a distinct role in adults’ views of their abilities for higher education.

Summary

Research on personal loss due to mental illness is grounded in a previous literature base of other types of loss and grief (Davis & Schultz, 1998; Harvey, 2002; MacGregor, 1994). Stein and colleagues (2005) have conceptualized personal loss due to mental illness as distinct from grief and other types of loss, encompassed in various categories of loss including loss of roles,
loss of routine, loss of former relationships, loss of former self, and loss of future. Research on personal loss due to mental illness has been studied within the context of families (Stein & Wemmerus, 2001) and adults with psychiatric disability (Stein, 2005). This research indicates that greater personal loss is associated with various losses in other areas of their lives, such as greater loneliness (Stein, Dworsky, Phillips, & Hunt, 2005), less positive well-being (Stein, Dworsky, Phillips, & Hunt, 2005), and lower aspirations and self-perceived capacity to attend college (Stein, 2005). However, little is known about the experiences of personal loss due to mental illness for children of parents with mental illness. Do these children experience personal loss due to their parent’s mental illness? Is personal loss related to other aspects of these young adults’ lives? Research is needed to examine the role of personal loss among the lives of those affected by their parents’ mental illness.

Religiousness and Spirituality in Young Adults

Research indicates that adolescence and early adulthood mark a stage of religious exploration and development (Bryant, Yun Choi, & Yasuno, 2003; Holcomb & Nonneman, 2004; Watson, Morris, & Hood, 1988). Researchers have conceptualized religious exploration as the examination of one’s faith, one’s purpose in the world, and the meaning of life (Bryant & Astin, 2008). As such, a common feature of this exploration is spiritual struggle (Bryant & Astin, 2008; Johnson & Hayes, 2003). Researchers have been particularly interested in the notion of spiritual struggles among college students, examining the various correlates and consequences associated with spiritual struggle (Bryant & Astin, 2008; Exline, Yali, & Sanderson, 2000; Johnson & Hayes, 2003; Pargament, Desai, McConnell, 2006). Yet, no research has investigated the religious and spiritual lives of young adults coping with a parent with mental illness.
In order to provide a rationale for the present research, a review of the literature on the religious and spiritual lives of college students is provided, focusing specifically on their faith development and the predictors and consequences of spiritual struggle. First, however, definitions of various terms are needed. Pargament, Desai, and McConnell (2006) define spirituality as “a search for the sacred” (p. 122). Sacred is defined as “things that are holy, set apart from ordinary aspects of living, and worthy of veneration and respect” (p. 122). Thus, the sacred includes many aspects of life, provided they are connected to a higher power (e.g., the Koran, worship, marriage, education, etc). The search is defined as “the process of discovery of the sacred, efforts to conserve or hold on to the sacred once it has been discovered, and attempts to transform the sacred when internal or external pressures insist on change” (p. 122). Religion, on the other hand, is regarded as “the larger social and institutional context in which the search for the sacred takes place” (p. 122). Thus, spirituality is always experienced within one’s religious practices.

Faith Development Among College Students

Regarding research on faith development during the college years, some researchers have found that religious and spiritual decline is common during this time period. Using a longitudinal design, Bryant, Yun Choi, and Yasuno (2003) studied the religious and spiritual dimensions of 3,680 college students from 50 four-year colleges and universities during their first year. Results indicated that students’ self-rated religiousness and spirituality declined during the first year of college. However, students’ self-rated commitment to integrating spirituality in their life increased during the first year. Thus, students continued to increasingly value spirituality, even though they rated themselves as less spiritual and religious at the end of year one.
Some studies have looked at the type of circumstances during the college years that may lead to changes in one’s faith. Holcomb & Nonneman (2004), for example, used a mixed method design to look at faith development in a sample of 240 randomly selected college freshman from six Christian liberal arts colleges and universities. Students were asked to recall key experiences that led to changes in their religious/spiritual thinking and believing. Preliminary results after Time One indicate that the experience of crisis, defined as a “prolonged period of active engagement with, and exploration of, competing roles and ideologies” (p. 100), was a key driver in faith development. In addition to these results, it is interesting to note that a large subset of undergraduates described their key experience as coping with a parent with mental illness. Results, however, did not indicate how this experience affected their faith development.

Pargament’s (2007) theory on the “search for the sacred” may be helpful in shedding light on “key experiences” and their association with faith development. According to Pargament, humans are goal-directed beings, who shape their lives in an effort to strive for whatever they hold spiritually significant or sacred. Pargament feels that this search is a motivating force that can help explain various decisions that people make in life, spiritually and otherwise. Along the search for the sacred, Pargament contends that persons move through various processes in order to maintain a relationship with the sacred. The three main processes in the search for the sacred include discovery, conservation, and transformation of the sacred. Though a detailed explanation of this theory is beyond the scope of this paper, a brief overview is provided below.

The first process in the search for the sacred is the discovery of something sacred (Pargament, 2007). Once the sacred is discovered, people follow various paths in order to conserve the sacred. Sometimes, however, efforts to conserve the sacred are challenged by
various stressors, threats, or violations, at which point one’s established beliefs about the sacred can be shaken. During this time, the process of *spiritual coping* often takes place. Thus, one tries to find a way to cope with his/her circumstances by either *preserving existent pathways* to the sacred or *creating new pathways* to the sacred, both of which aim to sustain a sense of connection with the sacred.

Sometimes, however, even one’s best efforts to hold on to the sacred are threatened to such an extent that old pathways to the sacred are no longer seen as viable (Pargament, 2007). When one’s previous ways of understanding the sacred are shaken, people often *struggle with their spirituality* to find new ways to understand the sacred. During this spiritual struggle, persons can either go through the process of *spiritual transformation* or *spiritual disengagement*. *Spiritual transformation* involves making radical changes in one’s life in order to develop new paths toward the sacred. *Spiritual disengagement*, on the other hand, involves a complete disconnection from and loss of interest in one’s search for the sacred.

According to Pargament (2007), when one goes through a *spiritual transformation*, he/she will begin new efforts to *conserve* the new sacred pathways. Those who experience *disengagement* from the sacred, on the other hand, may stay permanently *disengaged* from the sacred, they may *rediscover* the sacred, or they may experience a *transformation* in their search for the sacred. After this transformation of the sacred, the previously disengaged individual then returns to methods of *conserving* his/her new path to the sacred. Pargament notes that the search for the sacred is ever-changing, and as such, the path will continues throughout one’s life. Pargament’s theory suggests ways in which various stressors may lead to spiritual struggle, and subsequent spiritual transformation or disengagement. This framework can help direct inquiry into the experiences of adults coping with a parent with mental illness.
Summary

Research on the college years suggests that faith exploration and development is particularly common during this developmental stage. Specifically, research indicates that spiritual decline is common during the first year (Bryant, Yun Choi, & Yasuno, 2003) and that having a parent with a mental illness may be a salient catalyst in the development of these young adults’ faith (Holcomb & Nonneman, 2004). It is unclear, however, how the experience of having a parent with mental illness affects one’s faith development. Given that the college years mark a time of deep reflection and faith development, this population may be especially prone to struggling with their spirituality when reflecting on their life situation. Pargament’s (2007) theory on the search for the sacred provides an overall framework that describes processes that individuals may go through after experiencing a stressful/threatening event which may inform research on adults coping with a parent with mental illness. However, research is needed to examine the experiences of young adults coping with a parent with mental illness and its association with their faith journey. It is important to review the literature on a specific process of the search for the sacred – that of spiritual struggle.

Spiritual Struggle Among College Students

One aspect of college students’ faith development, spiritual struggle, has been studied extensively by various researchers (Bryant & Astin, 2008; Pargament, Smith, Koenig & Perez, 1998). Spiritual struggle is defined as “efforts to conserve or transform a spirituality that has been threatened or harmed” (Pargament, Murray-Swank, & Ano, 2005, pp. 247). Pargament and colleagues (2006) have conceptualized spiritual struggles as manifesting themselves in three ways—as interpersonal struggles, intrapersonal struggles, and struggles with the Divine.
Interpersonal spiritual struggles involve a religious clash between an individual and his/her family, friends, and/or religious community (Pargament, Desai, & McConnell, 2006). One may have a disagreement with his/her congregation regarding a religious interpretation of divorce, for example. Intrapersonal spiritual struggle, on the other hand, involves one’s own self-doubt and questions about spiritual issues (Pargament, Desai, & McConnell, 2006). An example of this is a person’s own questions about the existence of a loving God. Finally, spiritual struggle with the Divine refers to anger toward God or feelings of castigation or abandonment by God (Pargament, Desai, & McConnell, 2006). For example, a person who has become paralyzed in a car accident may feel as if God has abandoned him/her. Although defined separately, it is important to remember that one can manifest spiritual struggle in more than one domain. In fact, Pargament and colleagues (1998) have found intercorrelations among the three different domains of spiritual struggle. Below is a brief review of the prevalence, correlates, and predictors of spiritual struggle among college students.

In a quantitative study of 3,493 freshmen from 46 college institutions, Bryant & Astin (2008) were interested in examining the prevalence and correlates of spiritual struggle. Results indicated that a sizable proportion of students reported frequently struggling with ideas of evil, suffering, and death (21%), frequently questioning their religious/spiritual belief (18%), feeling unsettled about religious/spiritual matters to a great extent (16%), and feeling disillusioned with his/her religious upbringing to a great extent (10%). Moreover, experiencing spiritual struggle was associated with greater psychological distress, poorer physical health, lower confidence in one’s competencies, and less religious growth. However, college students who experienced spiritual struggle also showed increases in openness to diverse religious/spiritual views and
increases in spiritual growth. This research suggests that spiritual struggle is associated with both positive and negative outcomes.

Other researchers have found positive and negative associations with spiritual struggle among college students. Pargament, Smith, Koenig, & Perez (1998), for example, assessed spiritual struggle among three different populations, church members in Oklahoma city during the bombing, college students facing a personal stressor, and hospitalized patients coping with a medical illness. With regard to the college sample, results indicated that more reports of spiritual struggle were related to poorer physical health, higher levels of emotional distress, and higher levels of psychosomatic symptomatology. Interestingly, reports of more spiritual struggle were also related to higher levels of stress-related growth. Similar results were also found in another study of college students experiencing a negative life event (Pargament, Koenig, & Perez, 2000).

Other studies have examined the predictors, rather than outcomes, of spiritual struggle. Johnson and Hayes (2003), for example, were interested in examining the distress related to religious/spiritual concerns, as well as distress related to other stressors (i.e., confusion about values, death of a parent, homesickness, etc) among 5,472 college students from 39 private and public colleges and universities. In general, about 44% of the overall sample reported distress related to their religious/spiritual concerns at least “a little bit,” with 26% of the sample reporting moderate to extreme distress in this area. Additionally, results indicated that distress related to stressors, such as confusion about values, problems with relationships, sexual concerns, and thoughts of being punished for one’s sins were predictive of distress related to religious/spiritual concerns. This study sheds some light into the various circumstances that may lead to spiritual struggle.
Summary

Research on spiritual struggle indicates that a sizeable portion of college students struggle with their spirituality (Bryant & Astin, 2008; Johnson & Hayes, 2003). Moreover, research suggests that spiritual struggle is associated with a variety of negative and positive outcomes (Bryant & Astin, 2008; Pargament, Koenig, & Perez, 1998), and that distressing events are predictive of spiritual struggle (Johnson & Hayes, 2003). Although research has studied spiritual struggle extensively among college students, no research has specifically examined spiritual struggle among young adults who have a parent with mental illness. Coping with a parent with mental illness is certainly a stressor that may lead to experiences of spiritual struggle. Research is needed to explore the experience of spiritual struggle among young adults coping with a parent with mental illness.

Using Qualitative Research to Address Limitations of Previous Research

A review of literature on young adults of parents with mental illness highlights the need to understand both negative and positive experiences of this population from the perspective of adults themselves. Within the scientific community, there is a growing recognition of the importance of giving children of parents with mental illness a voice, specifically through qualitative research (Aldridge, 2006; Cogan, Riddell, & Mayes, 2005; Pitman & Matthey, 2004).

In an article reviewing the experiences of children who live with a parent with mental illness, Aldridge (2006) makes several points regarding the importance of using qualitative methodology for understanding this population. First, Aldridge argues that qualitative methodology allows these adult children to express their views and experiences, often unheard in the scientific community. Moreover, qualitative research can provide an environment of trust between the interviewer and the interviewee, allowing for the possibility of richer data to be
obtained. To be sure, research suggests that the fear of negative and stigmatizing attitudes from others prevents children of parents with mental illness from seeking external social support, such as friends, professionals, and deities (Cogan, Riddle, & Mayes, 2005). Thus, not giving this population a safe space to communicate their experiences may contribute to these children’s open and honest disclosure of their experiences.

Additionally, the scientific community would also benefit from a qualitative inquiry into the nature of these young adults’ experience of personal loss due to their parents’ mental illness, as the majority of research on personal loss has focused on personal loss of adults with mental illness themselves (Stein, Dworsky, Phillips & Hunt, 2005; Stein, 2005). A qualitative methodology can provide examples of the lived experience of personal loss for this population and generate hypotheses for future inquiry about the nature of loss. Moreover, qualitative approaches can provide additional insight into the religious experiences of these young adults, especially with regard to their faith journey and associated spiritual struggles. Indeed, researchers have recommended the use of qualitative research to better understand the experience of spiritual struggle (Bryant & Astin, 2008).

The Present Study

The present qualitative research describes experiences of personal loss and religiousness/spirituality reported by nine college undergraduates coping with a parent with a serious mental illness. Existing research highlights individual deficits and risks associated with having a parent with mental illness, as viewed primarily from the perspectives of parents and mental health professionals (Biederman et al., 2001; Jacob & Johnson, 1997; Williams & Corrigan, 1992). This research indicates that this population is at risk for a variety of negative psychosocial outcomes, including decreased self-esteem (Williams & Corrigan, 1992), increased
psychopathology (Jacob & Windle, 2000; Williams & Corrigan, 1992), and inadequate social adjustment (Jacob & Windle, 2000). Moreover, previous studies tend to focus on children and adolescents whose parents have a mental illness, leaving the experiences of young adults largely unheard in the scientific community.

Previous research indicates that personal loss due to mental illness is a salient experience in dealing with mental illness (Stein, 2005). Previous research also shows the importance of religion for college students, especially as a time of religious development (Bryant, Yun Choi, and Yasuno, 2003) and associated spiritual struggle (Bryant & Astin, 2008; Pargament, Smith, Koenig, & Perez, 1998). Yet, more research is needed to understand the role of personal loss due to mental illness and religion for young adults in various life circumstances, including individuals coping with a parent with a mental illness.

In the present study, in-depth narrative accounts from nine undergraduates were examined to describe these young adults’ experiences of personal loss as a result of having a parent with mental illness, their faith journey and associated spiritual struggles, and their perceptions of the personal impact of coping with a parent with mental illness. The present study subscribes to a grounded theory approach to qualitative inquiry (Strauss & Corbin, 1998), with the goal of generating themes from participants’ accounts of their experience. However, given the semi-structured nature of participant interviews, four initial research questions helped to direct the nature of the present inquiry:

1. Do young adults describe experiences of personal loss due to their parents’ mental illness?
2. Do young adults’ accounts of their experiences of personal loss relate to their descriptions of their faith journey and spiritual struggles?
3. Do young adults’ accounts of their experiences of personal loss relate to their descriptions of the personal impact of coping with a parent with mental illness?

4. Do young adults describe positive and/or negative impacts of coping with a parent with mental illness?
METHODS

Participants

Ten undergraduate students from a Midwestern university whose parents were coping with a mental illness completed in-depth interviews about their experiences of personal loss and religiousness for the present research. One participant was subsequently eliminated from the study due to significant differences in his religious background and life circumstances than other participants. The sample for the present study consists of a total on nine undergraduates (6 women and 3 men) who ranged in age from 18 – 22 years. All participants were Caucasian, never married, with a range in their college standing (1 freshman, 5 sophomores, 2 juniors, and 1 senior). Participants’ college majors included film, psychology, biology, theater, education, environmental studies, digital cinema, and two-dimensional fine arts. In terms of religiousness, 4 (44%) of the sample identified themselves as Catholic, 2 (22%) identified as Non-denominational Christian, 1 (11%) as Lutheran, 1 (11%) as Agnostic, and 1 (11%) as having no religious preference. Refer to Table 1 for more information regarding the demographic and religiousness of the sample.

Table 2 summarizes the types of mental illness of participants’ parents. Six participants reported one parent with a mental illness (5 mothers; 1 father) and 3 participants reported that both parents were diagnosed with a mental illness. Most participants reported that they had learned about their parent’s mental illness in adolescence (childhood: 4; adolescence: 6; adulthood: 1).

Measures

The Life Experiences Interview was a semi-structured interview developed for the present study (refer to Appendix A). The interview consisted of open-ended questions designed to
assess participants’ experiences related to living with a parent with serious mental illness. As recommended by Strauss and Corbin (1998) in their work on grounded theory, *The Life Experiences Interview* questions were intentionally designed to be broad and open-ended to solicit participant experiences and give voice to participant views not currently considered in the existing literature. Probe or follow-up questions were also provided in the interview to solicit participants’ experiences regarding issues more directly related to current theoretical concepts (e.g., personal loss due to mental illness, spiritual struggles).

Initial interview questions gathered basic demographic information (refer to Appendix B) about the young adult and his/her parent with mental illness. Subsequent topics of the interview included questions about the nature of participants’ family life, including feelings of personal loss due to mental illness and experiences growing up with a parent with mental illness. Religious and spiritual topics included the use of religion and spirituality to cope with a parent with mental illness, chronological accounts of participants’ faith journey, spiritual struggle that was the result of coping with a parent with mental illness, and efforts to resolve various types of spiritual struggle. Finally, questions were asked regarding the impact of having a parent with mental illness. After the initial interview questions, participants were given the opportunity to share additional information not covered in the interview, in an effort to allow participants to voice additional information that was meaningful to them.

Because of the breadth and depth of topics covered in *The Life Experiences Interview*, four sections were selected for qualitative analysis: participants’ descriptions of personal loss that were the result of having a parent with mental illness, their faith journeys, their spiritual struggles related to coping with a parent with mental illness, and the impact of having a parent with mental illness. These sections were selected because of the patterns that emerged in the data
during the beginning stages of data analysis. Below is a detailed discussion of these four sections of the interview.

Participants were asked about their sense of personal loss due to their parents’ mental illness. These questions were designed to assess the amount of disruption participants may have faced growing up in such a home and included questions consistent with the theoretical concept of personal loss due to mental illness found in the literature (Stein, Dworksy, Phillips, and Hunt, 2005). The current literature on personal loss due to mental illness identifies five categories of loss, and participants were asked whether they experienced loss in these five categories: the loss of normal roles of mother/father/child, the loss of normal routine in the household, the loss of friendships or relationships with others, the loss of a sense of oneself, and loss of or worry about the future, all as they relate to coping with a parent with mental illness.

Participants were also asked to describe their religious faith journey. This question was intentionally open-ended and broad, allowing participants to recall their journey of faith in ways that were meaningful to them. Participants were asked to recall aspects of their journey related to their parent’s mental illness, as well as where they currently saw themselves on their faith journey. This section provided a temporal account of each participant’s journey of religious faith.

Participants were also asked about any spiritual struggles they had experienced as a result of coping with a parent with mental illness. Participants were first asked about general spiritual/religious questions and concerns. Then, participants were asked about the three types of spiritual struggle as defined in the literature – interpersonal, intrapersonal, and Divine (Pargament, Desai, & McConnell, 2006).

Participants were also asked about the personal impact of having a parent with mental illness. After the participant was given the opportunity to respond in his/her own words, the
researcher followed-up with specific prompts regarding the impact that this experience had on them emotionally and physically. Additionally, participants were also asked how this experience impacted their views on marriage/family and their relationships with others. Finally, participants were asked how this experience affected their views about themselves, and their personal strengths/limitations.

A total of three pilot interviews were conducted to refine *The Life Experiences Interview* developed for the present research. Feedback and discussion about the interview was solicited from each interviewee and changes in wording and order of interview topics was made as a result of the three pilot interviews.

**Participant Recruitment**

Participants were recruited from sixteen introductory undergraduate classes in a variety of departments, including art, music, biology, chemistry, environmental studies, geology, and Spanish. Professors were contacted via email and/or personal meeting in order to obtain permission to send an announcement of the research project to students in the class. From these 16 classes, about 1,300 students were sent the announcement, resulting in an initial response of 27 students (See Appendix C for recruitment letter).

Potential participants contacted the researcher via email to set up a screening interview. Screening interviews were conducted over the phone and lasted about 5-10 minutes. In order to be included in the study, participants needed to be between the ages of 18-30 years and have a parent with a psychiatric diagnosis with whom they have lived for at least 5 years.

Additionally, participants were asked screening questions about the religious/spiritual aspects of their lives. Specifically, participants were asked about their religious/spiritual background, their idea of God, and whether there were aspects of their lives that they held
sacred. *Sacred* was defined to participants as *aspects of ultimate importance that were regarded as being connected to a Higher Power, transcendent, boundless, lasting, or something very important that goes beyond the self.* In order to be included in the study, participants needed to regard something in their life as sacred in order to obtain a sample who viewed their religion/spirituality within the parameters described by Pargament and colleagues (Pargament, 2000; Zinnbauer & Pargament, 2005). These screening criteria resulted in 10 participants who qualified for the study. (See Appendix D for screening interview, Appendix E for reasons for participant exclusion, and Appendix F for demographic information on the pool of potential participants).

**Procedure**

Participants completed individual, audiotaped, interviews that lasted about one to two hours. All interviews were conducted by the principal researcher and young adults were paid $25 for their participation in the interview. Field notes were written by the principal researcher after each interview that described the researcher’s impression of the interview and the participant, noted any emotional reactions displayed in the interview, and highlighted any particularly noteworthy points discussed in the interview. These initial field notes were used in developing working hypotheses during the initial stages of data analysis.

*Interview Transcription and Data Analytic Strategy*

Interviews were transcribed verbatim by a team of six research assistants. The research assistants used a tape recorder to listen to the interview, transcribing interview material verbatim into a written document. Research assistants were trained to similarly format the interview, noting pauses and emotional responses that took place during the interview. Each interview took
approximately 12-18 hours to transcribe, and transcripts were approximately 20-30 pages in
length.

After the initial verbatim transcription was complete, the principal researcher and another
research assistant checked the accuracy of each transcription by listening to the taped interview
and following along with the transcription. This process took approximately 1-3 hours per
interview.

After each transcript was checked for accuracy, the principal researcher read through
each transcript a number of times. Notes were made summarizing the sections of each interview
in the margins of the transcript, with care being taken to summarize all points made by
participants in each interview. The summary was intended to maintain the content and temporal
sequence of the interview, but to take out redundancies and verbal fillers, such as “um” and “ah.”
After these notes were made by the researcher, they were compared to the initial transcription to
ensure that all substantive points from the interview had been included. In addition, a separate
journal was kept throughout the data analysis process to record hypotheses and observed
response patterns in the data.

From these participant summarizations, an analytic memo was then constructed for each
participant. The purpose of the analytic memo was to maintain the content of the interview, but
to reduce the data into a more manageable and coherent summary, eliminating its original
temporal sequence. Each analytic memo was approximately 10-15 pages in length. Participants’
analytic memos were organized according to the sections of the interview. Each section was
summarized according to the notes, using quotes as exemplars of various categories within that
section. When a particular section produced responses that could be categorized in more than
one section, these responses were recorded in all appropriate sections in order to create a memo
that would be complete when compared across participants. Various interview topics that didn’t follow the initial protocol were extracted from the interview and placed in a separate section in order to ensure that all elements of the interview were contained in the analytic memo. The process of reducing a transcription into an analytic memo took approximately 12-15 hours per transcript, depending upon its length and the degree to which the interview maintained its structural outline.

After completing an analytic memo for each participant, the principal researcher compared each memo to its interview, assessing whether all elements of the interview were included in the analytic memo. The process of comparing each memo to its corresponding transcription lasted about 2 hours per memo. After this initial comparison, another research assistant read through two randomly selected analytic memos, comparing them to the original transcript. Feedback was provided about the accuracy of the analytic memo as compared to the transcript, and minor changes were made. Another accuracy check involved a comparison of all the transcripts to their corresponding analytic memos by the principal researcher, taking approximately one hour per memo. During this final read through, the principal researcher paid specific attention to components of the interview that were left out of the analytic memo. After this accuracy check, another independent rater read through two additional randomly selected memos, again compared to the original transcript. Minor changes were made, according to the feedback given.

**Cross-Sectional Analysis and Data Theming**

Analytic memos were then aggregated according to the various sections within the interview and compared across participants (e.g., faith journey responses for all participants). Data analytic procedures described by Miles and Huberman (1984) and Taylor and Bogdan
(1998) were used in analyzing the data. Thus, emphasis was placed on the fluid process of data analysis, as well as diligently keeping track of emergent concepts, ideas, and themes by creating tables and diagrams. For each interview section, participants’ responses were placed into tables and diagrams, tallying similar responses and making note of similarities and differences among participants. Participants’ responses were diagramed in a variety of ways to allow a variety of patterns to emerge in the data, facilitating the development of initial hypotheses. The process of creating tables and diagrams for each interview section took approximately 5-15 hours per interview section.

Due to the large amount of data collected from these interviews, there was a need to select a smaller subsample of data from the interview in order to report the results in a meaningful, coherent way. After attempting to organize participant responses in various ways, initial research questions were reviewed and used to organize data based on grouping participants’ responses into categories as a function of their views about personal loss due to mental illness. Accounts that focused on aspects of religiousness, specifically descriptions of participants’ faith journey and spiritual struggles, and the impact of having a parent with a mental illness were organized as a function of grouping individuals according their experience of personal loss.

The process of comparing participants’ responses within the faith journey, spiritual struggle, and impact sections as a function of loss of personal loss due to mental illness took approximately 8-10 hours per section. To facilitate this process, participant responses were grouped in a table according to similarities in their reported personal loss. Summaries of participants’ responses from the other three sections (faith journey, spiritual struggle, and impact
of having a parent with mental illness) were then placed in the table according to these groupings.

Before developing themes as a function of personal loss, various checks were made to ensure that personal loss categories could not be explained by various demographics, such as type of parental diagnosis, number of parents with a diagnosis per participant, and number of parents in each loss group. These initial checks indicated that type of parental diagnosis and number of parents with a diagnosis per participant did not appear to differ between the two personal loss groups. Additionally, initial checks indicated that there were 7 parents in the small loss group and 5 parents in the large loss group.

Themes were then developed according to these groupings, and exemplar quotes were gathered as representative quotes for each theme. In order to check the reliability of the themes and quotations for each section reported in this manuscript, lists of quotations and themes were given to a research assistant who matched themes to quotations. Quotations matched with 95% accuracy were kept as representative quotes for various themes.

Preliminary analyses were also conducted to compare participants’ reports of spiritual struggle to the existing measures of spiritual struggle, the NRCOPE (the Negative Religious Coping subscale) and Religious Red Flags scales. The analyses are beyond the scope of the current research, but a brief description of the data analytic procedures and preliminary results are included in Appendix K. Also included in this Appendix are tables cataloguing participants’ responses according to the NRCOPE and the Religious Red Flags scales.
RESULTS

Personal Loss due to Mental Illness

As part of the interview, participants were asked about their sense of personal loss as it relates to having a parent with mental illness. Young adults were asked, “Have you ever felt a sense of loss that is a result of your mother’s/father’s condition and what that was like for you?” Participants were then asked questions that related specifically to the five types of personal loss as defined in previous research by Stein and colleagues (Stein & Wemmerus, 2001; Stein, Dworsky, Phillips, & Hunt, 2005).

Participants’ responses were categorized into these five types of personal loss due to mental illness: loss of normal roles of mother, father, and children, loss of a normal routine in their home, loss of a sense of self, loss of friends or relationships with others, and loss or worry about the future. Overall, the two most frequent categories endorsed by participants were the loss of normal roles of mother, father, and children and loss or worry about the future. Each category of loss was endorsed by at least four participants. Loss categories endorsed by each participant, as well as an exemplar quote for each participant are found in Table 3. Refer to Table 4 for the number of participants endorsing each type of loss.

Based on the number of losses articulated by each participant, the sample was then divided into two groups: participants who described a relatively small number of losses (1-3 losses) and participants who described a relatively larger number of losses (4 – 5 losses). It is assumed that participants who identified losses in more categories were experiencing a greater range of personal loss in their lives as it relates to having a parent with mental illness. Within the Small and Large Loss groups, all categories of loss are represented, even though they are not
represented by every person within that group. Exemplar quotes are illustrated below for each loss group. See also Appendix G for a range of responses of loss within in each group.

Small Loss Group

The five young adults in the small loss group described between one and three types of personal loss due to their parents’ mental illness. All five types of personal loss were represented across the responses of the five young adults in this group.

The majority of participants (4 out of 5) in the Small Loss Group felt a loss of roles of mother, father, and child as it relates to having a parent with mental illness. For example, Billy, an 18 year old male coping with a mother with PTSD and depression and a father with an anxiety disorder and depression, comments on assuming a parental role within his home:

“She [My mother] would get to the point where she wasn’t really able to take care of my brothers and so I would have to…She said I wouldn’t have to, but I knew I had to take it upon myself to do that … I was babysitting them and stuff anyways, so it wasn’t that big of a deal…”

Two participants in the Small Loss group also felt a loss of routine as it relates to having a parent with mental illness. For example, Rachel, a 20 year-old female coping with a mother with depression, comments:

“I’d say no routine we kept…’d go to school, and then I’d work after school, and we’d [mom and Rachel] get back home around the same time, have dinner, and then she’d just go up into her room.”

One participant in the Small Loss group felt she lost a sense of who she was. Denali, a 20 year old female coping with a mother with depression and cyclophoria, talks about losing a sense of herself, especially as it relates to her religious beliefs:

“I went through a really long period of [religious] questioning, especially through that time [finding out about mom’s illness], which is really interesting when I think about it.”

One participant in the Small Loss group felt a loss of relationships as it relates to having a parent with mental illness. Kevin, a 20 year old male coping with a mother with bipolar disorder, feels that his friendships weren’t as good in quality as they may have been otherwise:
“Maybe not a loss of friends, but not as good of friends because I wouldn’t have friends over nearly as much as I might go to that person’s house. I wouldn’t have them over nearly as much.”

A total of two participants in the Small Loss group also reported a loss of a future as it relates to having a parent with mental illness. Jackson, a 20 year old male coping with a father with depression, obsessive-compulsive disorder, and seasonal affective disorder, as well as a mother with an anxiety disorder, feels similarly as it relates to his future schooling:

“I worry about what would happen to my dad a lot – how I would deal with that, how it would affect our family…with either parent I worry about how will it affect my future. Especially if something happened to them tomorrow – I’ve still got a brother in high school and a sister in junior high. And that would just completely alter my life… if something happened to them, like right now, I would have to drop out of college.”

Large Loss Group

Four participants met the criteria for the Large Loss group, endorsing 4-5 types of personal loss and all five types of loss were represented in responses from this group of participants.

All of the participants in the Large Loss group reported that they felt a loss of roles as it relates to having a parent with mental illness. For example, Lindsey, a 22 year old female coping with a mother with depression, talks about having to be a mother to her sister:

“My sister couldn’t turn to my mom for questions, so I would be the one that she would have to turn to, and she still does. And not just in a sisterly way…my mom should be dealing with some of the things she’s going through, but my sister can’t turn to her right now because of what’s going on. Because she feels like she can’t get a level-headed answer or she feels like it’s going to be too much for my mom to deal with.”

Steph, a 22 year old female coping with a mother with depression and a father with depression and bipolar disorder, comments about the extent to which she felt a loss of roles within her home. Specifically, Steph feels like her grandparents replaced her parents:

“My grandma and my grandpa kind of like stepped into that role of being the mom and dad for awhile. So, I got very used to and very close to them right away. But it only got me so far until I realized I don’t want them to be my mom and dad. I want my own mom and dad.”
Finally, 3 of the 4 participants felt a *loss of routine* as it relates to having a parent with mental illness. For example, Steph talks about how the normal routine with her father changed after he was diagnosed with depression:

“Dad used to help me with my homework and when all of that happened, he wanted nothing to do with that…So, it was almost like, what I knew, what I would look forward to, just sort of disappeared you know, [in] just such a short period of time.”

All participants in this group also expressed a *loss of a sense of who they were*. Julie, a 19 year old female coping with a mother with depression and substance abuse/dependence issues, talks about losing a sense of herself as a trusting, open person:

“I would cry and cry about it, and this [didn’t] affect my mom enough to make her want to do anything. So, I eventually, I hardened… I feel like I can’t be vulnerable, I feel like I don’t even have the ability to be vulnerable. And I don’t have the ability to trust easily. I feel like I need to be strong all the time.”

Steph also talks about losing a sense of self in a couple of different ways:

“I used to feel a lot of loss because I got so wrapped up in my home life that I decided to give up on everything else. Like, I didn’t care about school, I didn’t care about my sports. I gave up on sports. I pretty much shut down because my dad shut down…I lost myself for a while, and then on top of that, I lost my dad… As far as religion, that also is affecting this too because I don’t know who to believe anymore or what to believe because I’m so upset about what’s going on.”

In addition to a loss of a sense of self, 3 of 4 participants in the Large Loss group also felt a *loss of relationships with others* as a result of their parents’ mental illness. Lindsey, for example, feels like her friendships were affected because of her mother’s condition:

“Even our friend relationships were getting strained because we would not have the energy or the time to deal with the outside people. So, much was going on inside.”

All the participants in the Large Loss group also mentioned that they worried about their future as it relates to having a parent with mental illness. Kelly, for example, worries that she and her brother will develop drinking problems in the future, like their father:

“The biggest thing I worry about is - I haven’t drank before, but I’m worried if I do, like when I turn 21 and go to the bars, that I’ll turn into what he turned into, and it will be like the same pattern all over again.”

Lindsey’s worries, on the other hand, are slightly different. She worries about having to put her future on hold because of her mother:
“I worry about it a little bit because she’s constantly in need of my support…it’s to the point that I can’t do certain things without feeling guilty. I have planned something here over the summer to catch up on my degree, [but] because she’s going through so much and struggling, I can’t do it right now. I’m kind of worried that if I go out of state to school, find a job, or take a semester overseas that it’s really going to hurt my relationship with my family.”

Faith Journey

Participants were asked to respond to the question, “Do you ever think about your faith or religion as a journey? If not, how do you think about your faith? If so, can you describe your religious or spiritual journey?” This section was intentionally open-ended, allowing each participant’s experience to be recalled from his/her perspective. Participants recalled their faith journey in a variety of ways, using metaphors such as used “going through different parts of the country,” “a movie,” and “running a race.” Others recalled their faith journey more literally.

A follow-up question was asked regarding the aspects of the religious/spiritual journey that related to having a parent with mental illness. It is interesting to note that the majority of participants (8 out of 9) described aspects of their faith journey that were related to having a parent with mental illness. These aspects will be described in more detail in the Spiritual Struggles Section.

From the faith journey narratives, a chronological map was created for each participant’s faith journey. These maps served as a visual illustration of the chronological narrative recalled by the participant, including elements of the faith journey that corresponded to having a parent with mental illness. The creation of each map allowed sequential patterns to be observed in the data, especially as it relates to the differences between the two loss groups. Refer to Appendix H for these detailed maps.

The most notable patterns that emerged between the two loss groups were descriptions regarding where participants currently saw themselves on their faith journey. Below is a detailed
description of these results. Refer also to Table 5 for brief descriptions of participants’ reports of their current position on their faith journey.

*Faith Journey as a Function of Personal Loss*

*Small Loss Group*

When grouped according to loss groups, patterns in the data seem to suggest that participants in the Small Loss group are currently content with their religious/spiritual beliefs and their current position on their faith journey, despite not knowing exactly what to believe about their faith.

Rachel, for example, describes the process through which she came to peace with her faith. She reports the beginning of her faith journey as inactive. When she was 8 years old, she was baptized into the Mormon faith because she was told to do so, but still remained inactive in that faith. When Rachel’s mother was diagnosed with depression, Rachel became angry with God for giving her mother depression. Additionally, Rachel recalls that her mother became more religious after being diagnosed with depression and would encourage Rachel to go to church. This resulted in conflict between Rachel and her mother because she didn’t want to be involved with religion or forced into a religion she wasn’t sure about. Eventually, Rachel recalls reaching a point where she didn’t want to reject religion and God anymore. Now, she feels at “peace” with her current religious beliefs, even though she hasn’t decided on a religion:

“No, I’m just okay with where I am. I would like to be more religious, but that’s in the future. So right now, I’m just at peace with my situation.”

Similarly, Jackson describes his process of becoming sure of his beliefs. He describes the beginning of his journey as “twelve long years of Catholic education” where he was “force fed” religious stories. Last year, Jackson describes struggling to figure out what he believed because
of dealing with his parent’s mental illnesses. He blamed God for giving his parents mental illness and wondered if he would ever end up with it.

Jackson feels that he grew out of this phase as a result of going on a Catholic retreat his senior year in high school. Jackson recalls this retreat as a “soul opening experience,” where everything suddenly felt like it made sense. At this point, Jackson began “working his way back into being a Christian again.” This experience made him realize that his life “wasn’t so bad” and that he shouldn’t blame God for what happened to his parents. When Jackson looks back on this period of questioning, he regards it as something that helped him search for his faith.

This year, Jackson is sure of his beliefs, but is taking steps to make sure that these beliefs are his own and not something that others are forcing him to believe:

“This year, I know what I believe in, but I’m taking my steps to make sure it’s what I believe in and not what somebody else is telling me to believe.”

*Large Loss Group*

When grouped according to loss groups, patterns in the data seem to suggest that participants in the Large Loss group are in a current, or very recent, state of feeling spiritually lost.

Lindsey, for example, recalls the journey, which has led to her current state of confusion. Growing up, Lindsey did not have many religious influences. Initially, her mother was “very non-religious” and would encourage Lindsey to question religion. Some members of her extended family were also “very Catholic.” Thus, in high school, Lindsey started to develop her own religious views, mixing her mother’s non-religious beliefs with Catholic beliefs.

In college, Lindsey’s beliefs and practices continued to be based on “her own religion.” Recently, Lindsey’s mother has gone off of her medication, and Lindsey feels this has made her mother become very religious. Consequently, her mother has begun to encourage Lindsey to
become more involved with the church. This was very confusing to Lindsey, and she feels like she’s lost her direction and doesn’t know what to do next:

“I feel like I’ve backtracked a lot religiously and spiritually, as far as my connection with what I had before…All of a sudden, my mom completely changed her views. Now, she’s very religious, and it’s gotten very, very confusing. Very confused. I’ve backpedaled a lot, and I feel like I’m…trying to figure out what to do next.”

Steph also describes a journey that has led her to currently feel lost. When Steph was younger, she recalls that she would turn to God in prayer to deal with her parents’ mental illnesses. As she got older, however, she began to notice her parents getting worse, even though they were also turning to God for help. At this point, Steph felt like she wasn’t getting support from her religion and began to question her religious beliefs. Additionally, Steph felt like the church abandoned her father in his time of need because her family didn’t have money to give to the church. Steph also lost all of her friends at the Catholic school she attended when they found out her dad was ill, resulting in her leaving that school. Because of these issues, Steph feels the church is “fake and judgmental.” These spiritual struggles have led Steph to feel lost in her faith:

“I feel like I’m lost and don’t know what I’m supposed to be doing…to figure the whole thing out.”

Spiritual Struggles

Participants were asked to respond to the statement, “Tell me about some of the religious/spiritual questions and concerns that having a parent with mental illness has raised for you.” After this open-ended question was asked, participants were asked more specific follow-up questions related to the three domains of spiritual struggle – interpersonal, intrapersonal, and Divine – “Have you experienced conflicts or tensions with your church community, with your family, or friends that relates to your mother/father having a mental illness? Have you experienced a sense of personal doubt about religion or spirituality, given your mother’s/father’s condition? Have you experienced frustration with God about your situation, having a parent with this type of illness?”
It is worth noting that the majority of participants (8 out of 9) reported spiritual struggles as it relates to having a parent with mental illness. Only one participant felt that having a parent with mental illness did not create any spiritual struggle for him.

From the spiritual struggle narratives, participants’ spiritual struggles that related to having a parent with mental illness were categorized into the three types of spiritual struggle – interpersonal, intrapersonal, and Divine, as defined by Pargament and colleagues (2006).

When participants were grouped according to their loss groups, it appears that participants experiencing loss in relatively more areas of their lives also tended to report more spiritual struggle, as well as spiritual struggles in a greater number of domains (inter, intra, and Divine). Below is a detailed description of these results. Refer to Table 6 for a list of spiritual struggles per person, catalogued according to spiritual struggle domains and the loss groups.

**Spiritual Struggles as a Function of Personal Loss**

**Small Loss Group**

On average, participants in the Small Loss group tended to report less spiritual struggle than did those in the Large Loss group. To calculate the average number of spiritual struggles for each participant within their loss group, the types of spiritual struggle reported were counted for each person within the loss group across all three spiritual struggle domains (inter, intra, Divine), and this number was divided by the total number of types of spiritual struggle per loss group. Refer to Tables 7a and 7b for the number of types of spiritual struggle per person, as well as the number of domains of spiritual struggle per person, for each loss group.

With regard to the number of spiritual struggles per participant, those in the Small Loss group reported an average of 4 spiritual struggles per person. This number is less than half of the
average number of spiritual struggles reported by the Large Loss group (Large Loss group = 10
spiritual struggles/person).

Moreover, one participant, Billy, reports having never experienced a spiritual struggle as it relates to having a parent with mental illness:

“I don’t really have any [religious/spiritual] questions…it [religion/spirituality] never was really, really prominent in my life.”

In addition to fewer reports of spiritual struggles in the Small Loss group, this group also tended to report spiritual struggles in fewer spiritual struggle domains (inter, intra, and Divine). Participants in these groups tended to report spiritual struggles in 0-2 of the spiritual struggle domains. Even when there were reports of spiritual struggles in all three domains from a particular participant, reports in at least one domain were said to be “brief” or struggled with only a “little bit.”

Rachel, for example, reports spiritual struggle in three domains. When Rachel talks about intrapersonal spiritual struggle, however, she mentions that this questioning was brief:

“I’d wonder, ‘Is there really a God who would do something to me?’ But it was just brief, because I became a bigger person, and realized that bad things happen to everybody.”

Thus, for participants in the Small Loss group, the average number of spiritual struggles is less, and these spiritual struggles occur in fewer domains, as compared to the Large Loss Group. Below are three examples, one from each spiritual struggle domain, of spiritual struggles for those in the Small Loss group. Refer to Appendix I for a range of responses of spiritual struggle from this loss group.

Jackson, for example, mentions struggling with the church’s view on suicide:

“The Catholic church used to teach…that if you commit suicide you’ll automatically go to Hell. And I just don’t agree with that. It’s something they can’t really help. I mean they’re really suffering…Anybody who goes through that much suffering – how can you say they weren’t justified? I think any God that just automatically damns somebody to Hell because they killed themselves or because they were really depressed is not really that merciful of a God. I just don’t agree with that, spiritually.”
Denali talks about questioning her religious beliefs, especially after finding out about her mother’s depression:

“I went through a really long period of questioning [my religious beliefs], especially through that time [finding out about mom’s depression], which is really interesting when I think about it.”

Rachel, who is coping with a mother with depression, talks about her anger at God:

“I was just mad. I was so mad because I couldn’t understand why… I was just frustrated because I would have to help her all the time, and… she was sad all the time and tired. And I was just mad that I had to deal with it. And I was mad that it didn’t happen later, or earlier, where I’d be too young to have to do anything about it. And I prayed, but it would be angry. I’d be scolding God, while I’m praying. And I’d just be so frustrated, and angry.”

Also noteworthy for this group is that the majority of participants (4 out of 5) do not mention a spiritual/religious conflict with their ill parent. This is in contrast to the Large Loss group, where the majority of these participants (3 out of 4) have experienced spiritual/religious conflict with their ill parent. Thus, those participants experiencing loss of a normal life in less areas of their lives seem to also be experiencing less religious conflict with their parent with mental illness.

In terms of participants’ perceptions of the positive/negative impact of their spiritual struggle, the majority of participants in the Small Loss group viewed the impact of their spiritual struggle as positive. One participant initially regarded these struggles as negative, but now sees them as a positive experience that enabled him to grow religiously. Refer to Table 8 for a brief summary of participants’ perceptions of positive and negative growth from spiritual struggle.

Rachel talks about the positive impact of her spiritual struggles – developing a relationship with God:

“I don’t think I’d have much of a relationship with God if the things that happened to me didn’t happen… Why put a band-aid on if you don’t have a cut?… It’s good that I pray in my eyes. It’s good that I pray, it’s good that I have some sort of religious views. It’s also bad because my mom had depression; it had to take something negative to make a positive.”
Large Loss Group

The Large Loss group differs from the Small Loss group in a variety of ways. First, the average number of spiritual struggles reported by participants in the Large Loss group is 10. This number is more than double that of the Small and Medium Loss groups (4 spiritual struggles/person). Thus, for those participants who experienced loss of a normal life in more areas of their life also seem to experience a greater number of spiritual struggles.

Additionally, participants in the Large Loss group experienced spiritual struggles in all three of the spiritual struggle domains (inter, intra, and Divine), compared to 0-2 of the domains for the Small Loss group. Below are examples of participants’ responses from the three spiritual struggle domains. Refer to Appendix I for additional responses of participants in this group.

Steph, for example, talks about her interpersonal spiritual struggle, especially as it relates to receiving little support from the Catholic Church:

“…to have a church judge you like that and turn their back on you…they were fake to me and, you know, …they’ll go through life and if that’s what their going to do, they’ll have to deal with it later…But it was just kinda hard to believe that the church can be so much about money and politics…Normally, when you think of a church, you think you’re going to something deep, and they reach out and they help you to get through that bad time. And I don’t feel like they did that at all.”

Julie, on the other hand, recalls experiencing intrapersonal spiritual struggle and reports eventually losing her belief in Christianity:

“If God is omnipotent and great, why would He do this to my mom? Why would He do this to me? Why isn’t He helping me? Why isn’t He offering us any help? Everyone talked about how great God was, but I just had never really personally saw that work in my life.”

Lindsey also talks about intrapersonal spiritual struggle, especially as it relates to her religious confusion as a result of her mother’s change in viewpoint:

“After she went off of her medication, I went through a period where I actually lost a lot of connection with it, and I’m still trying to find it. For some reason, her views changed after she got off the medication, which was really odd for me. She’d been teaching me a certain way for so long, and then it completely, drastically changed.”
With regard to spiritual struggle with the *Divine*, Kelly, recalls feeling as though her prayers for her father were never answered:

“When he first got sick, I would pray every single day that he would get better. And I would just pray that God would hear me, and he’ll get better. I prayed every day for probably six straight months, and then he just kept getting worse. So, I prayed a little less and prayed for different things. When he had organ failure I just stopped praying all together.”

In addition, Steph talks about turning away from God after watching her mother receive little help from Him:

“I see my mother doing everything possible she can – great woman – looking up to God for help and trying…just turning to Him and hoping, ‘Just give me a break, you know?’…And it hasn’t yet happened, so that’s really made turn away from God because I just don’t understand why someone’s life has to be so horrible, and they don’t do anything to deserve it…Was she put on earth just to be set an example of someone that just had a crappy life?”

Particularly noteworthy for this group is that the majority of participants (3 out of 4) report experiencing spiritual/religious conflict with their ill parent. Julie, for example, talks about conflict with her mother over God’s ability to help her mother:

“We would argue, you know, ‘If God’s so great, why hasn’t he helped you?’ And my mom would always be like, ‘He will.’ And I would be like ‘Well, when?’ And we would just argue about stuff like that and I would tell my mom…that God isn’t real cause he doesn’t do anything.”

With regard to participants’ perceptions of the positive/negative impact of their spiritual struggle, the majority of participants (3 out of 4) in the Large Loss group initially regarded the impact of their spiritual struggles as negative. However, these participants also mention their resolve to find some type of faith belief system in the future, and they regard this aspect as positive. As mentioned in the faith journey section, these participants currently do not feel connected with their religion/spirituality and feel lost, but they also mention their motivation to find a belief system. Refer to Table 8 for a brief summary of participants’ perceptions of positive and negative growth from spiritual struggle.

Lindsey, for example, talks about the positive and negative impact of her spiritual struggles, and her resolve to prove to God she can “find her way” again:
“I can kind of see them [spiritual struggles] as both…I feel like it’s definitely negative that I’ve gotten so far from where I was, and that I don’t have the connection. But at the same time, I feel like it’ll be proving something to God to show Him that I can find my way back. Through everything that’s going on, I can still find my way back and be able to connect with Him.”

Impact of Having a Parent with Mental Illness

Participants were asked to respond to the question, “How do you think your experiences in coping with your mother’s/father’s illness have impacted you as a person?” Participants were then asked follow-up questions about the ways in which their parent’s mental illness impacted them emotionally and physically, how their parents’ mental illness affected their views on marriage and family, relationships with friends/family and how their parent’s mental illness impacted their views of themselves in the world and their strengths and limitations. Refer to Appendix J for exemplar quotes related to participants’ impact of having a parent with mental illness.

Impact as a Function of Personal Loss

When participants’ responses were categorized into two groups as a function of their reports of personal loss, participants experiencing less loss in their lives also tended to feel they were impacted less negatively. Additionally, participants experiencing loss in more areas of their lives also tended to feel more negatively impacted by having a parent with mental illness. What is interesting to note is that all participants, no matter their placement in a loss group, tended to view themselves as strong, independent, and compassionate individuals. The following is a detailed description of the various components of participants’ lives in which participants felt impacted, grouped according to the loss groups.
Emotional and Physical Impact

Small Loss Group

Refer to Table 9 for a brief description of each participant’s emotional and physical impact, grouped as a function of loss. Participants in the Small Loss group did not feel that their parent’s mental illness had an impact on their physical well-being.

Emotionally, however, these participants reported experiencing both negative and positive emotional impacts. In terms of more positive emotional impacts, just less than half of the participants (2 out of 5) tended to feel that their parent’s mental illness helped them to better understand emotions, especially those of an extreme nature. Kevin, for example, comments:

“I think it made me experience a bunch of feelings growing up…other people might have the perfect family—mom and dad, picket fence, brother and sister and nothing ever happens…they grow up their whole life being happy. What happens if all of a sudden their mom dies or dad dies? They don’t know sadness. But I’ve experienced all that. I don’t think you can experience true love without having the experience [of] other types of feelings.”

The majority of participants (3 out of 5) in the Small Loss group, however, also mention negative emotional impacts as it relates to coping with a parent with mental illness. These emotional impacts include feeling angry/frustrated, drained/stressed, and unloved.

Denali, for example, recalls feeling stressed and unloved as a child:

“Emotionally, I was really stressed when I was little – frustrated. It was just really hard to understand why. It was like I just really felt unloved sometimes, like she just didn’t care.”

Large Loss Group

In contrast to the Small Loss group, all participants in the Large Loss group reported feeling both physically and emotionally taxed as a result of having a parent with mental illness. Steph, for example, talks about the emotional effects of having to cope with a parent with mental illness:

“I do get so emotionally drained and stressed out and worried that I can’t focus…It’s been draining me for a very, very long time, and I feel like since I grew up in such a stressful environment and just constantly worrying, I don’t know what it’s like to relax anymore. I always feel stressed out…So, emotionally, it’s really done a number on me.”
Lindsey also talks about the emotional and physical impact of having a mother with mental illness:

“Emotionally, it’s been a roller coaster... Lots of confusion still to work through... Physically, it’s a struggle not to take it out on [myself] physically because I used to when I was younger. And I had been hospitalized for it... When I am dealing with it, it’s horrible to go back there.”

Kelly talks about feeling physically, emotionally, and mentally impacted:

“I think it [father’s illness and death] made me weak as a person, like emotionally, physically, and mentally.”

Views on Marriage and Family and Relationships with Family and Friends

Participants’ views on marriage and family, and their views of their relationships with family and friends were typically discussed together by participants. Thus, they will be described together in this section. Refer to Table 10 for a brief description of each participant’s views on marriage and family and relationships, grouped as a function of loss.

Small Loss Group

Overall, participants in the Small Loss group felt that growing up with a parent with mental illness fostered a positive view of marriage, even if their future spouse would have a mental illness. Additionally, these participants also felt that they were more understanding of mental illness, in general.

Jackson, for example, feels that he can have a normal marriage and family life, even if his spouse has a mental illness:

“You can really have a normal family life and a normal marriage even with depression. I mean, you’re gonna have to make exceptions but, that’s part of married life anyway. It’s just another part of the game.”

Kevin also feels his parent’s mental illness has impacted his views on marriage and family in a positive way:

“If I’m truly in love and my spouse has bipolarness, that’s not gonna deter me... from her cause she can’t help that. I think I could help her or be there more for her and understand her more.”
Denali also talks about how coping with a parent with mental illness made her understand mental illness:

“It made me really compassionate because of having to go through that and seeing how much of a struggle...it made me understand depression as a whole, whereas, I think a lot of people will see depression as almost like it’s their fault.”

**Large Loss Group**

The majority of participants (3 out of 4) in the Large Loss group, on the other hand, tended to have more negative views on marriage and love. Kelly, for example, doesn’t believe in love or see a point in marriage:

“I don’t think it’s possible for parents to have like a normal relationship cause I’ve never really seen that with anybody...I’m not a firm believer in love. I just don’t see marriage as a big of a deal as people see it.”

All participants in the Large Loss group also felt like that had a hard time trusting others, as a result of their parent’s mental illness. Julie, for example feels coping with her mother’s condition has made it difficult for her to trust others:

“It’s just very hard for me to trust people. People have to earn my trust. I’ve just always got to be skeptical about people until I know them pretty well.”

Steph also talks about having a difficult time trusting others as a result of her parents’ mental illness:

“I don’t get very close to people, and I have a lot of trust issues and stuff, just because I was kinda hurt when I was younger.”

All participants in the Large Loss group also tended to feel that their relationship with their ill parent was negatively impacted by their parent’s mental illness. Lindsey, for example, talks about having a difficult time communicating with her mother:

“Being able to be 100% truthful with her is still really hard, or being able to talk with her...I’m still struggling with talking with her about those things.”

Although the Large Loss groups seems to be negatively impacted in terms of relationships and views on marriage, half of the participants in this group (2 out of 4) also
mentioned that their friendships had improved or strengthened as a result of coping with a parent with mental illness. Lindsey comments:

“[Relationships with friends/family are] better with everybody ‘cuz I feel like I am more conscious about other people now…I feel like the relationships I do have with people, I really work on. If I do make a mistake, I really apologize for it, and try to fix whatever I do. And I try to listen more now.”

Views of Self, Strengths, and Limitations

Participants’ views of themselves, as well as their perceived strengths and limitations that are the result of having a parent with mental illness were also discussed together by these young adults. There seems to be no distinction in young adults’ views of these issues as a function of personal loss. Regardless of their experience of personal loss, participants tended to see themselves as growing positively from their experiences, and used words such as “stronger,” “independent,” “humble,” and “compassionate.” Specifically, 89% of participants saw themselves as stronger as a result of having to cope with a parent with mental illness. Additionally, 67% of participants saw themselves as more independent. Finally, 67% saw themselves as having a positive future, despite having grown up with a parent with mental illness. Refer to Table 11 brief descriptions of each participant’s views of themselves, their strengths, and their limitations, grouped as a function of loss.

Steph, for example, talks about her strengths:

“I know I’m a very strong person. Where I got that from, I’m not sure because my parents are both very weak people. Maybe it’s because they’re so weak, that’s why I’m so strong. I think growing up with mental illness my whole life has given me the ambition and the strength to do something in life. Because I don’t want to just throw it away, and I don’t want to be anything like my parents.”

Rachel gives another powerful example of her strengths, as well as her lack of limitations:

“I feel like I don’t have any limitations. I’m very smart. In high school, I was Summa Cum Laude. I’m on the Dean’s list here. I do very well in my classes. I’m in intelligent organizations. I feel like because I have to do everything for myself, I’m smarter. I’m street smart and book smart…I will have a good future, I know, because I will get a degree. I’ll have good grades. I’ll be able to get into a good graduate program. I’m going to be successful.”
Similarly, Julie notes:
“It hurt a lot, but I really do feel like it made me stronger.”

Denali comments that coping with a parent with mental illness made her more independent:
“It gave me a lot of opportunities when I was younger to be self-sufficient and take care of myself. So…it was really hard, but I think at the same time, it was for the better.”

Although participants felt they possessed many strengths, the majority of participants (78%) also felt that having a parent with mental illness made it difficult for them to open up to others emotionally. Rachel, for example, comments on this issue:
“I don’t really discuss my emotions very well with my friends…my roommate – she knows some things. I’ll go in my room every once in awhile, and I’ll just need to cry, and she’ll be like…‘Why won’t you talk about it with me?’ And I just don’t do that.”

Kelly also talks about having a hard time opening up emotionally:
“I keep close friends not as close as they should be, cause I don’t want to lose them…I don’t let my guard down real easy…It bothers a lot of people that I can’t let anybody in.”

Similarities

Although the structure of the results highlight differences among participants, there are also striking similarities among the responses of these participants on various topics. Below is a description of these similarities, organized by topic area.

Faith Journey

With regard to participants’ faith journey, it is worth noting that the majority of participants (75% - 6 out of 8 participants) who experienced spiritual struggle that was connected to having a parent with mental illness also expressed needing/wanting to resolve their struggle, no matter their placement in a loss group. See Table 12 for participant reports of needing to resolve their spiritual struggle.
For example, Rachel, from the Small Loss group, recalls her transition from her spiritual struggle:

“I wasn’t really sure what to believe, and I was angry at God, and I was angry at my family (laughs). I was angry at my mom. I was angry at anyone who was happy (laughs). But…I just got over it. You hit a point where you just don’t want to…reject it [religion/spirituality] anymore, you don’t want to pity yourself anymore, you just wanna, like, get out of that hole.”

Julie, also from the Large Loss group, is currently working toward a resolution and is trying to find an acceptable idea of God and re-define Christianity:

“I feel like I’m working towards a resolution, and I feel like the ultimate resolution will be developing my own acceptable idea of a God or finding or re-finding Christianity and really believing in it, and being ok with it. I think that would be the ultimate resolution.”

Steph, also from the Large Loss group, talks about her hope for resolution in the future, despite currently feeling spiritually/religiously lost:

“I’m still resolving those issues [religious/spiritual] now as we’re speaking. How I’ll feel a year from now, or two years from now… I think it’ll be a lot more positive, and I’ll have a better outlook on everything… Yeah, I won’t ever give up on it [religion/spirituality]… it is something very important in my life. I do know when I pushed it out of my life totally, I didn’t like myself and I didn’t like that feeling. So, I don’t want to go back to that, so, I can only look forward now. I move forward and maybe ten years, maybe a little more, I’ll just keep doing that.”

Thus, it seems that the majority of those struggling with their religion/spirituality, also saw a resolution to their struggle, no matter how much loss they experienced as it relates to having a parent with mental illness.

**Spiritual Struggle**

While differences exist between the Small and Large Loss groups with regard to the nature of the spiritual struggles, similarities are also present. Perhaps the most noteworthy is that 8 of the 9 participants (89%), regardless of membership in a particular Loss Group, experienced frustration with God as a result of their parent’s condition. Eight out of nine (89%) also felt personal doubt or confusion as it relates to their faith. Additionally, all participants asked ‘why’ questions to God as it relates to their parents mental illness (e.g., ‘Why did this have to happen?’ ‘Why isn’t He helping us?’). Finally, there are participants in all three groups that mention a
spiritual struggle with their religious community (i.e., church, clergy, etc). As illustrated, these participants share similar experiences in coping with a parent with mental illness, even though some differences also exist.
DISCUSSION

The present, in-depth qualitative study examined the first person accounts of nine young adults who attended a Midwestern university to better understand the role of personal loss due to mental illness, spiritual struggle, and perceived personal consequences of having a parent with mental illness. Results from the present study suggest that participants who described a relatively smaller range of personal loss in their lives due to parents’ mental illness also reported being fairly content on their faith journey, experienced relatively fewer spiritual struggles, and positively viewed the impact of coping with a parent with mental illness on their lives. Conversely, participants who described experiencing a relatively larger range of personal loss in their lives also reported a sense of being lost on their faith journey, experienced relatively more spiritual struggles, and viewed the impact of coping with a parent with mental illness more negatively. However, the majority of participants, regardless of their experience of personal loss, described being motivated to resolve their spiritual struggle. Additionally, all nine participants described feeling stronger, more independent, and having a positive future as a result of coping with their circumstance.

Personal Loss due to Mental Illness

The present research extends prior research on personal loss due to mental illness in a variety of ways. First, previous research has indicated that grief and personal loss tend to be salient experiences for people with mental illness (Stein, Dworsky, Phillips, & Hunt, 2005; Stein & Wemmerus, 2001) and for parents coping with a child with mental illness (Davis & Schultz, 1998; Ryan, 1993; Stein & Wemmerus, 2001; Solomon & Draine, 1996). The present research suggests that young adults experience personal loss due to their parents’ mental illness and that it is a meaningful experience for them.
All participants in the study had no difficulty understanding the concept of personal loss due to mental illness and gave rich details regarding the ways they experienced feelings of loss. Young adults were able to articulate their experience of personal loss in ways that were consistent with previous quantitative work (Stein, Dworsky, Phillips, & Hunt, 2005) and give added meaning to the categories through their words. Participants’ descriptions suggest the importance of a life course perspective in contextualizing the experience of personal loss due to mental illness. For example, one study participant, Billy, reports feeling that mental illness leads to the loss of having a mother, and feeling that he had to be a parent for his siblings. Billy worried about having to give up his future goals in order to take care of his brother. Billy’s “loss of roles” and “loss of the future” was experienced and described within the context of family life.

In general, young adults’ perceived loss of roles include losses in terms of the loss of a mother/father, subsequent inappropriate roles taken on by the child (i.e., being a “parent” to an ill parent or to a sibling), and other role compensations to make up for the loss of a parental figure (i.e., grandparents stepping in as parents for the child).

Young adults’ perceived loss of or worry about the future included overall themes of worry about having to take care of the ill parent, and subsequently, having to give up one’s future career aspirations. This particular finding is consistent with research on grief among mothers with a child with schizophrenia, which suggests that these mothers experience a loss of freedom in their own lives as a result of their child’s illness (Ryan, 1993). In terms of young adults perceived loss of a sense of self, responses seem to relate to personal changes indirectly associated with the disruption that accompanied having a parent with mental illness, and seem to deal with an all-encompassing loss of identity (i.e., difficulty figuring out goals/beliefs, inability
to identify one’s sense of self, questioning religious/spiritual beliefs, giving up on one’s interests/aspirations).

These young adults’ perceived *loss of routine* to include a loss of an after school routine, a loss of a family holiday routine, and a loss of a homework routine, to name a few. With regard to the *loss of relationships with others*, young adults report losses that included elements of embarrassment or strain associated with coping with a parent with mental illness, particularly in terms of friendships (i.e., strained friendships, not inviting friends over/isolating oneself, and sabotaging romantic relationships). This particular finding is consistent with previous qualitative research, which indicates that isolation from others, and thus a loss of relationships, is a common mechanism for coping with a parent with mental illness (Kinsella & Anderson, 1996). Young adults’ responses about personal loss add to the literature by highlighting the types of losses that are specific to men and women in young adulthood who are coping with a parent with mental illness.

In addition, results from the present research extend previous research on personal loss by indicating that particular loss categories seem to be more emotionally significant for participants than other loss categories. In the present sample, the loss of roles of mother/father/child, loss or worry about the future, and loss of a sense of self were endorsed by a greater number of participants than other loss categories. Conversely, some loss categories, such as loss of routine and loss of relationships, seemed to be less emotionally significant for participants in the present study. For example, in the present study, Rachel talks about a changed holiday routine, and Steph talks about a loss of a homework routine, rather than an all-encompassing loss of routine in one’s life. Additionally, Kevin discusses not having very good quality friendships, rather than
a loss of friendships. These loss categories were endorsed by a fewer number of participants, suggesting that they may be less salient for young adults.

The present research on personal loss suggests that young adults experience personal loss to varying degrees and that the intensity of their experience personal loss may relate to religious aspects of their lived experience and the way they make meaning of the loss. This result is consistent with previous research by Stein (2005), which suggests that personal loss due to mental illness is related to other aspects of people’s lives, such as aspirations for higher education. Specifically, Stein found that various elements of personal loss were associated with fewer aspirations and plans to attend college and with self-perceptions of less intellectual and emotional capacity for college. Present findings examined the role that personal loss might play in young adults’ faith journey, spiritual struggle, and perceived impact of coping with a parent with mental illness.

Faith Journey Experiences as a Function of Personal Loss

Participants’ narratives about their faith journey are consistent with prior research that suggests that having a parent with mental health difficulties may be a key experience that drives the development of college students’ faith (Holcomb & Nonneman, 2004). Indeed, the majority of participants in the present study describe aspects of their faith journey that are related to having a parent with mental illness. The Holcomb and Nonneman study, however, did not make any conclusions regarding how this life circumstance (having a parent with mental illness) may affect college students’ faith journeys. Thus, the present research extends Holcomb & Nonneman’s research by suggesting that the degree to which personal loss is experienced may be one way to describe how having a parent with mental illness affects one’s faith journey. Specifically, the present research suggests that those who are experiencing a relatively greater
range of personal loss in their lives as it relates to having a parent with mental illness seem to feel more lost on their faith journey, while those experiencing personal loss to a relatively lesser extent seem to feel more content on their journey.

Pargament’s (2007) theory on the search for the sacred can be used to help understand the hypothesized relationship between young adults’ current position on their faith journey and their experience of personal loss. According to Pargament, various threats or violations to one’s search for the sacred can create confusion or disillusionment (e.g., spiritual struggle) as it relates to previous sacred paths. As mentioned, the majority of participants in the present research describe spiritual struggle as it relates to having a parent with mental illness. Rachel, for example, describes her disengagement from religion and anger at God because of her mother’s depression. Kelly, on the other hand, reports feeling spiritually lost after her dad was diagnosed with depression and alcoholism. It is hypothesized that the young adults in the present study could not sustain their familiar sacred pathways because of the stress of coping with a parent with mental illness, and as a result, began to experience spiritual struggle. This result is consistent with previous research, which indicates that spiritual struggle is a somewhat common response to college students experiencing a negative life event (Pargament, Koenig, & Perez, 2000).

Pargament’s (2007) theory on the search for the sacred also suggests that spiritual struggle can lead to established ways of *conservational spiritual coping*. On the other hand, spiritual struggle also can lead to *spiritual transformation* or *spiritual disengagement*. Using this framework, young adults in the small loss group seem to have gone through either *conservational spiritual coping* (attempts to preserve current pathways to the sacred) or *transformational spiritual coping* (making changes to create new pathways to the sacred) as a
result of their spiritual struggle, in order to reach a place where they currently feel content in their faith journey.

For example, in the present study, Jackson describes feeling sure of his beliefs, after having resolved his anger at God during a Catholic Retreat. Thus, Jackson seems to have engaged in *conservational spiritual coping*, attempting to preserve his existent pathway to the sacred through the realization that he had no reason to be angry with God for his parents’ mental illnesses. Looking back, Jackson now regards the spiritual questioning related to his parents’ mental illness as the means that helped him to make sense of his faith. Indeed, Kinsella and Anderson (1996) also found that young adults reported making sense of their faith through the process of coping with parents with mental illness. In a similar vain, Mickley and colleagues (as cited in Pargament, 2007, p. 101) have also found that people are more likely to view negative events from a positive spiritual perspective than to view these events as accredited to an angry God. This previous research is similar to these young adults’ use of *conservational spiritual coping* to help them continue down their sacred pathway in the face of coping with a parent with mental illness.

In applying Pargament’s theory (2007), some participants in the small loss group seem to have instead gone through *transformational spiritual coping*. Denali’s description of the process through which she reconciled her spiritual struggle, for example, can be conceptualized in terms of *transformational spiritual coping*. Initially Catholic, Denali indicates that she struggled with her religious beliefs after her mother was diagnosed with a mental illness. However, after joining an on-campus religious organization this past year, Denali reports feeling a reaffirmation of her faith and feels she is now headed toward a more “liberal, spiritually-focused” Christian
perspective. Thus, Denali is beginning to create new pathways to the sacred in response to her reported spiritual struggle.

Overall, it is hypothesized that young adults from the small loss group may have been able to conserve or transform their spiritual pathways because of the relatively small extent to which they report feeling personal loss from their parent’s mental illness. Perhaps it is the case that experiencing a smaller amount of personal loss is less threatening or less of a violation to one’s faith journey. As such, these participants were able to conserve existent spiritual pathways or make the transition to new sacred pathways. Indeed, previous research indicates that college students who report greater distress in other areas also report greater distress related to religious and spiritual concerns (Johnson & Hayes, 2003). It should be noted, however, that the cross-sectional nature of this study prevents one from drawing causal relationships and pinpointing a specific cause for young adults’ changes in their faith journey. These speculations are hypotheses that would benefit from further research.

With regard to participants to who were experiencing personal loss to a relatively greater extent, these participants currently report feeling lost on their faith journey. Lindsey, for example, discusses the religious confusion surrounding her mother’s increase in religiousness, a change that Lindsey attributes to her mother going off of her medication. Lindsey had originally formed her own religious beliefs, in part, from her mother’s initial lack of religious beliefs. Because of this, Lindsey discusses feeling spiritually lost, not knowing how to make sense of her mother’s new religious convictions. This narrative is similar to other participants’ narratives in the large loss group, in that all of these participants report feeling spiritually lost on their faith journey.
According to Pargament’s (2007) theory, it may be that young adults from the large loss group are currently in the midst of spiritual struggle – these participants describe the current spiritual pain and confusion associated with coping with a parent with mental illness. Steph, for example, describes her spiritual struggle associated with her mother’s illness, such as feelings of abandonment and judgment from the church, religious confusion, feeling religion is a mind game, and blaming God for her mother’s condition, to name a few. Similar to participants in the small loss group, Pargament’s framework would suggest that participants in this group who are experiencing spiritual struggle may shift to conservational or transformational spiritual coping at some point. It is hypothesized that these young adults have not yet shifted to the process of conservational or transformational spiritual coping because the experience of personal loss due to their parents’ mental illness is too threatening. Thus, it may be more difficult to continue down previously established pathways or even create new pathways to the sacred, and they continue to struggle with their spirituality.

However, Pargament’s (2007) framework also suggests that these young adults may completely disengage from their faith journey, instead of engaging in spiritual conservation or transformation. It is worth noting that despite these young adults’ reports of feeling lost on their faith journey and potential for disengaging from their spirituality, they also express a motivation to resolve their spiritual struggle in the future. Steph, for example, reports that she is not willing to give up on her religious/spiritual beliefs, even though she currently feels spiritually lost and abandoned by her church. Additionally, Steph hopes to have a more positive spiritual perspective in the future. This finding corroborates with prior research, which indicates that college students continue to value spirituality, even though they show declines in the spirituality and religiousness during their first year (Bryant, Yun Choi, & Yasuno, 2003). As it relates to the
present research, these young adults may engage in *conservational* or *transformational* spiritual coping in the future, making radical changes in an effort to create new pathways toward the sacred. As Pargament notes, one’s faith journey is dynamic and ever-changing, evolving throughout the course of one’s life.

It is important to remember that one’s spiritual journey – and the conservation, transformation, or disengagement that may result from threats/violations to sacred pathways – may not be merely determined by a single factor. As Pargament (2007) comments, the search for the sacred is complex, and individuals can be affected on their faith journey by a variety and combination of experiences. It is interesting, however, to note that individuals experiencing relatively less personal loss report feeling more content on their spiritual pathway, and those experiencing relatively greater personal loss report feeling more lost on their spiritual pathway. Perhaps personal loss due to a parent’s mental illness is one of many significant determinants of spiritual change on one’s faith journey, particularly for young adult’s coping with a parent’s mental illness. More research is needed to explore the relationship between these spiritual changes and personal loss due to mental illness.

**Spiritual Struggle as a Function of Personal Loss due to Mental Illness**

Previous research has examined spiritual struggle within the context of college students experiencing negative life events, and indicates that college students do, in fact, experience spiritual struggle (Bryant & Astin, 2008; Pargament, Koenig, & Perez, 2000; Pargament, Smith, Koenig, & Perez, 1998). However, no research has specifically explored spiritual struggle among young adults coping with a parent with mental illness. The present research does suggest that young adults report spiritual struggle related to their parents’ mental illness and that this is a meaningful experience for them. Specifically, participants were able to articulate their
experience of spiritual struggle in ways that were consistent with previous quantitative and
theoretical work on spiritual struggle (Pargament, Desai, & McConnell, 2006; Pargament, Smith,
Koenig, & Perez, 1998). For example, in the present study, Jackson recalls interpersonal
spiritual struggle (struggling with the Catholic church’s view on suicide) and intrapersonal
spiritual struggle (confused about what to believe and stopped believing for a period of time)
associated with his parents’ mental illnesses.

Secondly, prior research has indicated that spiritual struggle among college students is
associated with various outcomes, such as psychological and emotional distress, physical
decline, and spiritual growth (Bryant & Astin, 2008; Pargament, Koenig, and Perez, 2000; Smith
& Harkness, 2002). Findings from the present research, however, identify a potential precursor
to spiritual struggle – personal loss due to parental mental illness. This result is consistent with
previous research that has identified various predictors (i.e., homesickness, relationship
problems) of religious/spiritual concerns among college populations (Johnson & Hayes, 2003).
Although causal associations cannot be drawn in the present research, it may be that personal
loss due to mental illness may be a unique predictor of spiritual struggle for young adults coping
with a distressed parent.

The present research extends previous research on spiritual struggle by providing detailed
qualitative accounts of the lived experience of spiritual struggle, a methodology recommended as
central to the study of spiritual struggle (Bryant & Astin, 2008). These qualitative accounts have
provided a richer understanding of the nature of spiritual struggle. Specifically, these young
adults, regardless of their placement in a loss group, talk about their spiritual struggles in ways
that seem emotionally salient to them.
For example, Rachel, even though a young adult in the Small Loss group, describes her anger at God in a way that seems charged with negative emotion,

“I was just mad. I was so mad because I couldn’t understand why. I couldn’t understand why my dad had to die, why my mom almost died… And I was just mad that I had to deal with it. And I was mad that it didn’t happen later, or earlier, where I’d be too young to have to do anything about it. And I prayed, but it would be angry. I’d be scolding God, while I’m praying. And I’d just be so frustrated, and angry.”

Steph, from the Large Loss group, similarly describes her intrapersonal spiritual struggle in an emotionally strong way,

“I see it my mother doing everything possible she can, great woman, looking up to God for help and trying…just turning to Him and hoping, ‘Just give me a break, you know?’…And it hasn’t yet happened, so that’s really made turn away from God because I just don’t understand why someone’s life has to be so horrible, and they don’t do anything to deserve it…Was she put on earth just to be set an example of someone that just had a crappy life?”

Even though the nature of spiritual struggle seems to differ as a function of personal loss, it also seems that spiritual struggle is an emotionally significant experience for young adults in the study. This result is consistent with previous research, which indicates that about 70% of college students report at least “a little bit” of distress associated with their religious and spiritual concerns (Johnson & Hayes, 2003).

The present research sought to examine the role that personal loss played in participants’ reports of spiritual struggle. Results suggest that those experiencing a relatively smaller amount of personal loss are also experiencing less spiritual struggle and spiritual struggle in fewer domains. In contrast, those experiencing relatively larger amounts of personal loss also tend to experience more spiritual struggle and spiritual struggle in greater domains. For example, Kevin (from the Small Loss group) discusses experiencing intrapersonal spiritual struggle and spiritual struggle with the Divine, both only for a “split second;” specifically, he recalls experiencing personal religious doubt and frustration with God as it relates to his mother’s bipolar disorder. Julie, on the other hand, is from the Large Loss group and reports spiritual struggle from all three spiritual domains (inter, intra, and Divine); she recalls religious conflict with her ill mother over
God’s ability to help her mother, wondering if religion was a trick, and feeling betrayed and unloved by God, to name a few. These results suggest that varying degrees of personal loss are associated with varying degrees of spiritual struggle.

In the present study, participants who describe experiencing relatively more personal loss also tend to report more religious conflict with their ill parent. Previous research has tended to highlight interpersonal spiritual struggle with clergy and church members (Pargament, Smith, Koenig & Perez, 1998; Smith & Harkness, 2002). The present research extends previous research by indicating that interpersonal spiritual struggle with family members may be a particularly salient experience among families who have a member with mental illness. There are a couple of hypotheses that can explain this finding. First, previous research indicates that various mental health difficulties, such as paternal and maternal depression, are associated with impaired parent-child interaction and increased parent-child negativity (Jacob & Johnson, 1997). Other research also suggests that maternal depression is associated with more negative and less positive affective styles in problem-solving interactions between a mother and child (Hamilton, Jones & Hammen, 1993). Thus, religious conflict between parent and child may be one of many conflicts young adults experience with their parents with psychiatric disability. Secondly, the experience of personal loss may play a significant role in religious conflict between parent and child, beyond that of paternal psychiatric disability. No research has assessed the relationship between personal loss due to parental mental illness and religious conflict between parent and child. Future research would benefit from the study of these variables.

Impact of Having a Parent with Mental Illness as a Function of Personal Loss

Young adults’ accounts of their personal impact of coping with a parent with mental illness in the present study appear to relate to their descriptions of personal loss. Specifically,
those who feel personal loss to a relatively greater extent also feel more negatively impacted by their parents’ mental illness. Conversely, those experiencing personal loss to a relatively lesser extent tend to feel more positively impacted by their parents’ mental illness. Previous research on personal loss indicates that increased levels of personal loss is associated with other negative variables, such as reports of fewer aspirations and plans for college (Stein, 2005), less positive intellectual and emotional capacity for college (Stein, 2005), more loneliness (Stein, Dworsky, Phillips, & Hunt, 2005), and more severe and distressing psychological symptoms (Stein, Dworsky, Phillips, & Hunt, 2005). The present research, however, adds to our understanding of ways that personal loss might be related to other aspects of young adults’ experience.

The present results that young adults who report relatively greater personal loss tend to also report perceived negative impacts deserves some attention. Although participants did not specifically comment on the relationship between personal loss due to mental illness and perceived impact, it is interesting to speculate on possible ties. First, relatively greater levels personal loss seems to be associated with a perceived negative impact on one’s relationships. Participants’ reports of greater personal loss seem to also be associated with more negative views of love and marriage. It may be that these young adults feel a greater sense of disillusionment in terms of relationships and love and marriage because of the perceived negative impact that their parent’s mental illness has had on their relationships with others. Similarly, it also may be that young adults’ perceived personal loss negatively impacts their views on love and marriage.

It also appears that those participants experiencing greater personal loss also feel that their friendships were strengthened. Previous qualitative research suggests that young adults with a parent with mental illness report turning to friends and other family members as a means to cope with their parents’ mental illness (Kinsella & Anderson, 1996). Other research also
indicates that friends and grandparents are important sources of social support for these young adults (Mowbray & Mowbray, 2006). It may be that personal loss due to parental mental illness creates a void that needs to be filled in order for participants to feel supported and comforted. Thus, these young adults may turn to friendships in order to find comfort and support.

Results from the present study also indicate that those experiencing personal loss to a relatively lesser extent tend to report more positive personal impacts, in terms of positive views of marriage/love and feeling more understanding of others with mental illness. Again, there is not enough information to understand the reason for these findings. However, prior research indicates that adolescents and adults of parents with mental illness can experience a diversity of outcomes, both positive and negative (Mowbray, Bybee, Oyserman, Allen-Meares, MacFarlane, & Hart-Johnson, 2004; Mowbray, Bybee, Oyserman, MacFarlane, & Bowersox, 2006). For example, Mowbray and colleagues (2005) found that certain clusters of adolescents of mothers with mental illness had lower peer involvement and social competence, while other clusters indicated higher levels of peer involvement and social/interpersonal competence. This study suggests certain variables (i.e., social support by the ill mother) are predictive of the diversity of outcomes experienced by these offspring. This research also notes that various predictors of outcomes among this population are complex and are not necessarily associated with one specific variable. With regard to the results from the present research, it is hypothesized that personal loss due to parental mental illness may be another contributor to the diversity of perceived impacts reported by young adults of parents with mental illness.

Results from the present research indicate that participants report positive views of themselves, their strengths, and limitations, regardless of the amount of personal loss they report. Previous quantitative research underscores the risks and deficits associated with having a parent
with mental illness (Mowbray, Bybee, Oyserman, MacFarlane, & Bowersox, 2006; Jacob & Windle, 2000). When given the opportunity to discuss their perceptions, all participants in the present research mention positive impacts, such as feeling stronger, more independent, and more positive about their future. This research is consistent with prior qualitative research examining perceived strengths of young adults of parents with mental illness (Kinsella & Anderson, 1996). Specifically, young adults in Kinsella and Anderson’s study describe feeling independent, creative, empathic, resilient, and assertive as a result of coping with a parent with mental illness. The present research also corroborates with Marsh and colleagues (1993) whose research on offspring of parents with mental illness indicates that 86% of those surveyed reported positive consequences in their experiences with a family member with mental illness.

Study participants also discuss some personal limitations, such as feeling more emotionally closed to others, regardless of their experience of personal loss due to mental illness. Consistent with previous research (Jacob & Windle, 2000; Biederman et al., 2001; Stromwall & Robinson, 1998), present results also suggest the potential vulnerability of young adults coping with a parent with mental illness.

Limitations of the Present Research

Although the present study provides interesting insights into the experiences of young adults with a parent who has mental illness, the research is limited in several respects. Sample characteristics and self-selection factors due to sample recruitment must be considered in understanding present results. The present sample consisted of a small number of young adults from similar backgrounds. Thus, the experiences of a larger number of young adults from more diverse backgrounds may yield different results. In addition, the majority of parents of these young adults were said to be diagnosed with anxiety disorders, affective disorders, and/or
alcohol abuse/dependence issues. As such, similarity of diagnoses may contribute to the nature of the results. Some participants in the present research are coping with two parents with mental illness, rather than one, which may create more complex issues for those individuals. Additionally, recruitment materials indicated that the study was particularly interested in the religious and spiritual lives of young adults of parents with mental illness. Thus, the sample may be self-selected such that interested participants are those that are “spiritually-searching” and may not include the insights of those who are less motivated to discuss issues of religion and spirituality. Finally, individuals were prescreened for the present study to increase the likelihood that the sample could articulate their spiritual or religious experiences. Thus, experiences of young adults who are less spiritual or less articulate in describing their spirituality may have different experiences than those reported in the present research.

The qualitative, cross-sectional nature of the research does not allow causal inferences to be made between study elements. The present study is framed in terms of participants’ experiences of personal loss, a conceptual framework found to be useful in previous research (Ryan, 1993; Stein & Wemmerus, 2001; Stein, 2005). However, alternative frameworks may be equally applicable in understanding the narratives of participants. Stein and Mankowski (2004) note that the researcher interprets the experience of participants in conducting qualitative research, and does not simply summarize it. Of course, quantitative researchers also select a conceptual framework for interpreting their results. As with all good research, the present study relied on various methods to establish the reproducibility and trustworthiness of the study results.

As suggested by leading qualitative methodologists (Taylor & Bogan, 1998; Miles & Huberman, 1984), the present study makes explicit the framework used to interpret qualitative data and provides a detailed account of the entire data analysis process. In the present study, all
interviews were conducted by the principal researcher to allow for a degree of standardization across interviews. Detailed notes were taken throughout data collection and analysis to facilitate working hypotheses. Moreover, the researcher made every effort to reflect all elements of participants’ narratives in the analytic memos, even if topics did not follow the semi-structured interview. During data analysis, alternative frameworks were explored to see if narrative themes could be explained by such things as participant demographic information or parent diagnosis. Research assistants conducted reliability checks at various points throughout the research process, to examine the accuracy of transcriptions, completeness of analytic memos from written transcriptions, and the reproducibility of theme categories and representativeness of participant quotes.

Implications and Directions for Future Research

Despite these limitations, the present research has a number of implications for both research and practice. First of all, the present research highlights the benefits of using a qualitative approach for this population. Participants’ narrative accounts of their experiences allowed for a richness of information to be obtained, informing prior research and theory on personal loss, faith journeys, spiritual struggle, and the personal impact of coping with a parent with mental illness. With this approach, participants were given the opportunity to share both positive and negative aspects of their experience, rather than only the commonly reported deficits and risks. Thus, the present research suggests the importance of using a qualitative perspective in order to gain a better understanding of these participants’ experiences and to advance prior research and theory.

Previous research suggests that children of parents with mental illness experience a sense of stigma, preventing them from seeking social support and discussing these issues openly.
(Cogan, Riddle, & Mayes, 2005). Other research has highlighted the potential importance of providing opportunities for various marginalized groups, such as young adults who have a parent with mental illness, to make meaning of their experiences (Rappaport, 1995; Stein & Wemmerus, 2001). Similarly, researchers have suggested that people may achieve a better understanding of themselves through the process of the self-reflection inherent in the participation of qualitative interviews (Alderidge, 2006). Thus, the present research provided an opportunity for participants to reflect upon their experiences and share their views of loss, spirituality, and the meaning. Traditionally, this population might only have the opportunity to examine such issues in the context of a helping setting such counseling or psychotherapy. As Stein and Mankowski (2004) note, the opportunity for marginalized groups to have caring others such as research interviewers “witness” their personal stories has implications for the direct contribution that psychology research can make in the lives of study participants.

Of course, the present study raises almost as many questions as it answers. Future research is necessary to better understand the role of personal loss and religion among more religiously diverse samples and for adults at various periods of the life course. Research is needed to better describe the impact of the type of parental mental illness (i.e., bipolar disorder, schizophrenia, personality disorder) on adults’ experience of loss, spiritual struggle and faith journey. Longitudinal designs are needed to better describe the direction of relationships between personal loss, spirituality, and a range of psychological and physical outcomes for adults across the life course. The present study offers an important first step in the development of empirical measures of personal loss for adult children coping with a parents’ mental illness.

Despite its limitations, the present qualitative research offers an intriguing look into the lived experience of young adults coping with a parent with mental illness. The study highlights
the potential importance of personal loss in describing the faith journey, spiritual struggles and perceived impact of mental illness in the lives of these adults. Future research is needed to understand the generalizability of current results and to extend our understanding of the role of religion in the lives of people faced with challenging family circumstances.
REFERENCES


I. Introduction

Before we get started, I’d like to briefly explain what we’ll be doing here today. I am working on my master’s thesis in clinical psychology here at BGSU and this interview will serve as partial fulfillment towards that degree. I will be asking you a series of questions today about your experiences growing up with a parent with mental illness, and how these experiences may or may not have affected you spiritually, physically, mentally, and emotionally. I am especially interested in learning the ways that spirituality/religion may or may not have been a source of comfort or a source of struggle for you as a result of having a parent with a mental illness.

The information that you share will remain completely confidential. I will be audio-taping this interview, but no names or any other identifying information will be directly associated with your responses. The audio-taped interview will be transcribed and the audio-tapes will be erased no later than one year after the completion of the research. Quotations from your responses may be used in the dissemination of the results, but your name and other identifying information will be changed in order to maintain your confidentiality.

As a token of appreciation for your participation today, you will receive $25 after the completion of this interview.

Though I have a series of questions for you, I am interested in your personal experiences of these events and would like you to answer openly and honestly. Also, please feel free to ask for clarification if there is anything that seems unclear. Finally, your participation in this interview is completely voluntary, so please feel free to skip any questions or to stop the interview at any time.

II. Demographics

Refer to Demographic Sheet

III. Transition to college

So, you are a [year] in college. What has this year been like for you so far?


IV. Life Experiences

What was it like for you growing up with a [mother/father] who was coping with [name of illness]?
Probes: What types of changes did you notice in your mother/father? 
How did you make sense of the changes? 
What was family life like?

Sometimes people talk about feelings of loss that they experience when they have a parent coping with a mental illness. Feelings that they lost out on some parts of a normal life. I am wondering if you’ve ever felt a sense of loss that is a result of your mother’s/father’s condition and what that was like for you.

Probes: If participant can not think of any losses they have experienced, then help define: 
Do you ever feel that there was a loss of normal routine in your house? What is that like for you? 
*Do you ever feel that there was a loss of normal roles of mother, father, children in your house? What is that like for you? 
*Do you ever feel that there was a loss of friends or relationships with others because of your mother’s/father’s condition? What is that like for you? 
*Do you ever feel that you lost your sense of who you are or what you were like before your mother’s/father’s illness? What is that like for you? 
*Do you ever think about or worry about your future because of your mother’s/father’s condition? Feel that you might have lost some of your future? What is that like for you?

V. Religion and Spirituality

General questions to get a sense of your religiousness and spiritual beliefs.

Probes: *Do you consider yourself to be a religious or spiritual person? What is that like for you? 
*Are there aspects of your life that you hold sacred? (e.g., of ultimate importance, things that are transcendent, boundless, lasting, something that’s most important to you or goes beyond yourself 
*Do you believe in God or a Higher Power? How do you envision God or a Higher Power?

Sometimes, people talk about religion or spirituality as a way to cope or make sense of their experiences. In trying to understand or cope with your mother’s/father’s illness, can you tell me about what role, if any, that religion or spirituality has played in that experience?

*Do you think that you get strength or support from your religion/spirituality? Also, from: A religious community? From God? From within yourself? Can you describe what this is like?

Tell me about some of the questions and spiritual concerns that having a parent with mental illness has raised for you.
Probes: If participant cannot think of any spiritual struggles, then help define: Spiritual struggles can be things like:

* Conflicts or tensions with your church community, with your family, or friends that relates to your mother/father having a mental illness;
* A sense of personal doubt about religion or spirituality, given your mother’s/father’s condition;
* Frustration with God about your situation --having a parent with this type of illness.
* Describe any images, pictures, or words that come to mind as you think about your spiritual struggle.
* What kinds of feelings have been tied to your spiritual struggle (e.g., anger, sadness, hurt, disappointment, guilt, loneliness, joy, happiness, excitement, hope)?

I am wondering if you can talk about where you see yourself now in terms of your spiritual struggles. Are there spiritual struggles or parts of the struggle that you feel you have resolved? What is that like for you? Are there spiritual struggles or parts of the struggle that you are still working on? What is that like for you? Can you talk about where you see yourself with regards to these struggles in 5 or 10 years?

Probes: If participant does not respond to each question –resolution of struggles; continued or ongoing struggles; anticipated future resolution or non-resolution of struggles, then inquire.

Sometimes people describe their faith or religion as a journey. Do you ever think about it this way? If not, how do you think about your faith? If so, can you describe your religious or spiritual journey?

Probes: If participant does not describe aspects of religious journey related to parent’s condition, inquire of and how the journey is related to having a parent living with a mental illness.

VI. Individual Well-Being

We have been talking about a lot of things today --what it is like having a parent with [name of illness], feelings of loss due to your parent’s illness, your sense of religiousness or spirituality. I’m wondering how you think your experiences in coping with your mother’s/father’s illness have impacted you as a person.

Probes: If participant does not spontaneously mention well-being, inquire:
Has having a mother/father with a mental illness impacted you:
Emotionally? Physically?
In terms of your relationships with family and friends?
Your views of marriage and family?
How you think about yourself in the world?
How you view your personal strengths and limitations?
How do you think your experiences coping with your mother’s/father’s illness have impacted your sense of religiousness or spirituality?

*If participant has previously mentioned going through a spiritual struggle, or is currently experiencing a spiritual struggle, then ask:

* How has your spiritual struggle changed you as a person, your relationship with other people, or your relationship with God? Have these changes been positive or negative? In what ways?

VII. Closing

I want to thank you for talking with me today. I have been asking you most of the questions, but I was wondering if there is something that is really important to my understanding your experiences that we haven’t talked about. Is there anything else that you would like to share for me to understand things better?

Do you have any questions for me?

Well, this now completes the interview. It has been a pleasure meeting you. I want to thank you for sharing your life experiences with me here today. What you have shared will help us better understand how people experience living with a parent with mental illness. Just to give you some information about my next steps in the process, I have a few more people that I want to talk with and then I will be reviewing what participants have talked about, looking for similarities and differences among what participants have shared. I want to reiterate that everything you have talked about today will remain confidential, meaning that your name or any other identifying information will NOT be associated with your responses. However, if you are interested in the overall results of the study, I can be in touch with you again to share what we’ve learned.
APPENDIX B

DEMOGRAPHIC SHEET

*Life Experiences Interview*
Demographic Information

1) Age: ___________

2) Gender: Male  Female

3) Year in School: ____________

4) Major: ____________________________

5) Marital status: ________________________________

Questions about your [mother/father’s] psychiatric condition:

6) What is your parent’s current psychiatric diagnosis? _______________________

7) At what age was he/she [your parent] given this diagnosis? ________________

8) At what age did you learn about this diagnosis? ___________________________

9) Has your parent been hospitalized for his/her mental health condition? Y  N
   a. How many times? _____________________________

10) Last hospitalization (month/year)? ________________________________

Religion/Spirituality:

11) Religious affiliation: ______________________________

12) Frequency of church attendance:

   Never       A few times/year      Once a month      Once a week       A few times a week

13) Overall level of religiousness:  1          2          3          4          5

   Not at all       Moderate       Very
APPENDIX C

RECRUITMENT LETTER

Hello BGSU Student,

My name is Aleisha Pfaff, and I am a graduate student in the clinical psychology program here at BGSU. I am currently working on my master’s thesis and looking for interested persons who are willing to be part of my research project. I am particularly interested in learning about issues of religion and spirituality for young adults who have a parent with mental health issues, such as major depression, bipolar disorder, or schizophrenia. I am especially interested in understanding your personal experiences regarding these issues.

In order to participate in this study, you must have a parent with mental illness, and you must be between the ages of 18 and 30 years. The information you share will remain confidential and your name will not be directly associated with your responses. Your participation will consist of talking with me privately for about an hour or so in a room in the psychology building. As a token of appreciation, you will receive $25 for completing the project.

If you are interested in sharing your experiences with me, please email me your name and phone number at ampfaff@bgnet.bgsu.edu, and I will contact you with more information.

I look forward to hearing from you. The information you share can help people better understand what it is like living with a parent with mental health issues.

Sincerely,

Aleisha M. Pfaff

-------------------------
Aleisha Pfaff
Clinical Psychology Graduate Student
Bowling Green State University
Bowling Green, OH
ampfaff@bgnet.bgsu.edu
APPENDIX D
SCREENING INTERVIEW

Hello. My name is Aleisha Pfaff, and I am calling regarding your response to my email about a research project that I am conducting. How are you doing this afternoon? Am I catching you at a good time? Good.

Well, first I wanted to give you a little more information about my project. As you probably remember from the email, I am interested in learning about issues of religion and spirituality for young adults who have a parent with mental health issues, such as major depression or schizophrenia. I am especially interested in learning about these issues from your own personal experience.

If you are interested in participating in this project, you and I will schedule a time when we can get together. Our appointment will consist of a 1-2 hour interview. The interview will be audio-taped, and every effort will be made to ensure your confidentiality. Your name will not be directly associated with anything you talk about in the interview. As a token of my appreciation, you will receive $25 upon completion of the interview.

Does this sound like something you are interested in?

Well, before we set up a time, I have some questions to ask you to get a better sense if this is something that you might want to be involved in.

Can you tell me how old you are?

Can you tell me about your parent’s diagnosis –do you know what type of illness your mother/father was diagnosed with?

How long have you known about your mother/father’s illness?

Did you grow up living in your mother/father’s house?

Have you lived with this parent for at least 5 years?

A portion of interview is going to focus on religious/spiritual issues, so I would like to ask you a few questions upfront about the meaning of religion and spirituality in your life.

Can you tell me a little bit about your religious or spiritual background?

How do you think about God? (envision, see, feel about…)

Are there aspects of your life that you hold sacred? (e.g., of ultimate importance, things that are transcendent, boundless, lasting, something that’s most important to you or goes beyond yourself).

Thank you for your time in answering these questions. It sounds like you have a lot of important things to say about your experiences as a young adult of a parent with mental illness. Let’s try to find a time where we can meet in person to do an interview.
APPENDIX E

REASONS FOR PARTICIPANT EXCLUSION

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<th>Number of participant responses:</th>
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<td><strong>Reasons for exclusion:</strong></td>
<td></td>
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<tr>
<td>International student</td>
<td>1</td>
</tr>
<tr>
<td>No response after initial contact by researcher</td>
<td>2</td>
</tr>
<tr>
<td>Did not hold anything sacred</td>
<td>2</td>
</tr>
<tr>
<td>Not sure about parent’s diagnosis</td>
<td>3</td>
</tr>
<tr>
<td>Contacted researcher after completion of recruitment phase</td>
<td>9</td>
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<tr>
<td><strong>Total participants:</strong></td>
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</table>
## APPENDIX F
### DEMOGRAPHICS FROM POOL OF POTENTIAL PARTICIPANTS

<table>
<thead>
<tr>
<th>Part #</th>
<th>Age</th>
<th>Gender</th>
<th>Parent’s Dx</th>
<th>Age Participant Learned of Dx</th>
<th>Sacred Objects</th>
<th>Eligibility</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>22</td>
<td>Female</td>
<td>Father: bipolar disorder</td>
<td>Childhood</td>
<td>Family Church</td>
<td>Yes</td>
</tr>
<tr>
<td>2</td>
<td>DK</td>
<td>Female</td>
<td>DK</td>
<td>DK</td>
<td>DK</td>
<td>No: international student</td>
</tr>
<tr>
<td>3</td>
<td>DK</td>
<td>Male</td>
<td>DK</td>
<td>DK</td>
<td>DK</td>
<td>No: no response after initial contact by researcher</td>
</tr>
<tr>
<td>4</td>
<td>19</td>
<td>Female</td>
<td>Father: depression, alcohol</td>
<td>Adolescence</td>
<td>No use of drugs/alcohol</td>
<td>Yes</td>
</tr>
<tr>
<td>5</td>
<td>18</td>
<td>Female</td>
<td>Mother: bipolar disorder, schizophrenia</td>
<td>Adolescence</td>
<td>Nothing</td>
<td>No: did not hold anything sacred</td>
</tr>
<tr>
<td>6</td>
<td>20</td>
<td>Female</td>
<td>Mother: depression, cyclothymia</td>
<td>Adolescence</td>
<td>Art</td>
<td>Yes</td>
</tr>
<tr>
<td>7</td>
<td>20</td>
<td>Male</td>
<td>Mother: bipolar disorder</td>
<td>Childhood</td>
<td>Bible</td>
<td>Yes</td>
</tr>
<tr>
<td>8</td>
<td>22</td>
<td>Female</td>
<td>Mother: depression</td>
<td>Adolescence</td>
<td>Relationships with family, friends, God</td>
<td>Yes</td>
</tr>
<tr>
<td>9</td>
<td>18</td>
<td>Male</td>
<td>Mom: PTSD/depression, Dad: anxiety/depression</td>
<td>Childhood</td>
<td>Family, Striving to be good</td>
<td>Yes</td>
</tr>
<tr>
<td>10</td>
<td>19</td>
<td>Male</td>
<td>Dad: depression, OCD, SAD, Mom: anxiety</td>
<td>Mom: Adolescence, Dad: Childhood</td>
<td>Crucifix, Faith, Family, friends</td>
<td>Yes</td>
</tr>
<tr>
<td>11</td>
<td>23</td>
<td>Female</td>
<td>Not sure about mother’s diagnosis</td>
<td>Adulthood</td>
<td>Family, friends</td>
<td>No: not sure about parent’s dx</td>
</tr>
<tr>
<td>12</td>
<td>21</td>
<td>Male</td>
<td>Mother: depression</td>
<td>Mother: childhood, Father: adolescence, Step-mother: depression</td>
<td>Morality, Self less service, Kindness, courtesy</td>
<td>Initially, yes, No: differences in religious background/life circumstances</td>
</tr>
<tr>
<td>13</td>
<td>27</td>
<td>Female</td>
<td>Not sure about father’s diagnosis</td>
<td>Adulthood</td>
<td>Family, Her son, Honesty</td>
<td>No: not sure about parent’s dx</td>
</tr>
<tr>
<td>14</td>
<td>DK</td>
<td>Female</td>
<td>Not sure about father’s diagnosis</td>
<td>DK</td>
<td>DK</td>
<td>No: not sure about parent’s dx</td>
</tr>
<tr>
<td>15</td>
<td>19</td>
<td>Female</td>
<td>Mother: depression, alcohol</td>
<td>Adolescence</td>
<td>Trust, Love</td>
<td>Yes</td>
</tr>
<tr>
<td>16</td>
<td>DK</td>
<td>Male</td>
<td>DK</td>
<td>DK</td>
<td>DK</td>
<td>No: no response after initial contact by researcher</td>
</tr>
<tr>
<td>17</td>
<td>19</td>
<td>Female</td>
<td>Mother: depression</td>
<td>Childhood</td>
<td>No</td>
<td>No: did not hold anything sacred</td>
</tr>
<tr>
<td>18</td>
<td>20</td>
<td>Female</td>
<td>Mother: depression</td>
<td>Adolescence</td>
<td>Interactions w/family Prayer</td>
<td>Yes</td>
</tr>
</tbody>
</table>
## EXEMPLAR QUOTES OF PERSONAL LOSS FROM THE SMALL AND LARGE GROUPS

<table>
<thead>
<tr>
<th>Loss Group</th>
<th>Participants</th>
<th>Loss Categories Endorsed</th>
<th>Exemplar Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small Loss</td>
<td>Billy Rachel Kevin</td>
<td>Loss of roles</td>
<td><strong>Loss of Roles</strong></td>
</tr>
<tr>
<td></td>
<td>Denali</td>
<td>Loss of routine</td>
<td>Rachel – “I felt like I was my mom’s mother a lot of the time. She sleeps all day on the weekends, so I’d go in and try to get her out of bed. I’d do things for her—I’d go to the grocery store for her, make sure she’s taking her medicines. She would always sleep with the T.V. on, and I’d always go in and turn it off after she falls asleep.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Loss of a sense of self</td>
<td>Denali – “She would come home every night from work and she would just go to bed. I’d never see her. She was just completely like a zombie. I feel like I had no mom for, like, three years. It was just really stressful. That was really hard because my mom would come home, and I’d wanna go do stuff with her, and I wanted to go out or. And she’d be like, ‘Ok, we’ll go out, just after a nap.’ And then she’d be out for the whole night. So, it was really, really frustrating.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Loss of relationships</td>
<td>Denali – “When my mom was on medication she was always asleep and I’d always go in and remind my brother to take his medicine. I was like the mom. And then I’d have to go remind my dad to do stuff. It was really frustrating cause I was thirteen years old, and I’m trying to run this household and, no one would like take me seriously.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Loss or worry about future</td>
<td>Kevin – “Everyone always thinks the mom is the one you wanna go to if you’re sad…The dad is the strict person, but my dad had to play both a lot. But my mom was still a mom and she wasn’t always in a bad attitude. But, it kind of took away from the stereotypical mom, dad—who you want to go to for a certain situation”</td>
</tr>
<tr>
<td>Small Loss</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Cont’d)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of Routine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rachel – “I guess the holidays changed a little bit. My mom is tired all the time, so Christmas shopping – she’d always be doing it last minute…everything’s last minute and kind of slopped together.”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denali – “Even now, there’s a little bit of routine in the house, but compared to some of my other friend’s families…I always thought that everybody was just kind of nutty and didn’t really have routines…our family’s just all over.”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss or Worry about Future</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Billy – “I worry that he’s not going to be around through both of my brothers’ high school years, and this may seem selfish, but I don’t wanna have to let go of my goals and dreams and stuff to come back and have to help out there.”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Large Loss</td>
<td>Kelly</td>
<td>Julie</td>
<td>Steph</td>
</tr>
<tr>
<td>------------</td>
<td>-------</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td>Loss of roles</td>
<td>Loss of a sense of self</td>
<td>Loss or worry about future</td>
<td>Loss of relationships</td>
</tr>
<tr>
<td>Julie - “When I was growing up, my mom never offered me any guidance. She never really took me anywhere, she never wanted to do anything, like me and her. And I would see all my friends going to lunch with mom, going shopping with mom, and I never really got to do any of that because, with my mom, it seemed like her life was work, come home, drink – her whole day, that’s what she’s looking forward to doing.”</td>
<td>Julie – “I feel like there was a role mix up … my mom would confide in me, my mom would come to me with her problems and ask me what to do. And I always felt like it should have been the other way around.”</td>
<td>Kelly – “It really is like losing somebody when my dad was battling depression…he wasn’t the same person anymore. I wouldn’t ever want that on anybody. I wouldn’t wish that on my worst enemy – for somebody’s parent to be like that.”</td>
<td>Kelly – “He wasn’t home anymore. He would go to bars, and we wouldn’t know where he was for days on end…that just scared my mother more than anything because she wanted to make sure he was okay. And if we would find out where he was, he would just stay in a hotel by himself …he just wasn’t around literally and figuratively … he just wasn’t there for you.”</td>
</tr>
<tr>
<td>Steph – “Once I lost my dad, my mom kinda went along with him. So, it was kind of like you lost both parents at the same time…she’s constantly stressed out working to support us by herself. And as much as she wanted to be there for us, she just couldn’t. She could only do so much. It was just kinda like raising yourself.”</td>
<td>Steph – “I kind of feel like I am my mom and dad’s strength. If it wasn’t for me, I don’t know what their lives would be like right now. And it’s kind of like a burden on my shoulders. I feel like instead of me being the child, I’m the parent.”</td>
<td>Lindsey – “I struggled with it…that period of time I definitely felt like it was hard to figure out my goals and what I believe in.”</td>
<td></td>
</tr>
</tbody>
</table>
| **Large Loss**  
<table>
<thead>
<tr>
<th>(Cont’d)</th>
</tr>
</thead>
</table>
| Lindsey – “I’ve struggled with it a lot. There are many decisions that I would like to make and I can’t make them right now because I’m stuck in this limbo…I feel really tied to my mom right now because she doesn’t really have it under control yet. I can’t go off and make my own decisions like a lot of people…I’m just kind of stuck in the school position.”  

Steph – “I don’t feel like I can depend on them, emotionally or financially, if I ever needed that situation. And then the future does worry me, because we have a pretty small family as it is, so, who else am I supposed to really depend on if I need something?”  

**Loss of relationships with others**  

Kelly – “I just would sabotage it [relationships with boyfriends] from the beginning and I still do, which is unfortunate.”  

Steph – “I would always make up stupid excuses and stuff like that to avoid those kind of things, or I would end up going to another house or doing something like that.”  

**Loss of routine**  

Julie - “My mom would never really make dinner or anything like that – we wouldn’t really have dinner. A lot of my friends would be like, ‘I gotta go, I get off the phone now. We’re gonna have dinner.’ [With] my mom, she’d come home she’d make dinner maybe once a week, sometimes she’d do some laundry. But usually when she came home, she was looking forward to one thing and that was drinking. So I mean we never really did that routine.”  

Lindsey – “It was a lot of staying up late, either to talk to each other, or just to isolate myself from things that were going on – just to get away from everybody for a while.” |
## APPENDIX H: MAP OF PARTICIPANTS’ FAITH JOURNEYS*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Faith Journey</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Billy</strong></td>
<td></td>
</tr>
<tr>
<td>Religion</td>
<td>– Went to church</td>
</tr>
<tr>
<td>not part of life</td>
<td>(b/c of his independence)</td>
</tr>
<tr>
<td><strong>Rachel</strong></td>
<td></td>
</tr>
<tr>
<td>Beginning:</td>
<td>– Then:</td>
</tr>
<tr>
<td>Inactive in</td>
<td>baptized:</td>
</tr>
<tr>
<td>her religion</td>
<td>still inactive</td>
</tr>
<tr>
<td></td>
<td>(Mormon)</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Now: @ peace w/ her beliefs: even though hasn’t decided on a rel</td>
<td></td>
</tr>
<tr>
<td><strong>Jackson</strong></td>
<td></td>
</tr>
<tr>
<td>Beginning:</td>
<td>– Blamed God: for</td>
</tr>
<tr>
<td>Force fed</td>
<td>making parents ill;</td>
</tr>
<tr>
<td>Catholic teachings</td>
<td>Questioned belief;</td>
</tr>
<tr>
<td></td>
<td>Last year: Catholic Retreat:</td>
</tr>
<tr>
<td></td>
<td>resolved anger at God</td>
</tr>
<tr>
<td></td>
<td>(Realized there’s no need to be mad)</td>
</tr>
<tr>
<td>This year:</td>
<td>Sure of beliefs.</td>
</tr>
<tr>
<td></td>
<td>No one will tell him what to believe</td>
</tr>
<tr>
<td></td>
<td>Feels his questioning pushed him to</td>
</tr>
<tr>
<td></td>
<td>explain his faith</td>
</tr>
<tr>
<td><strong>Kevin</strong></td>
<td></td>
</tr>
<tr>
<td>Faith Journey: Running a Race</td>
<td></td>
</tr>
<tr>
<td>Beginning of race:</td>
<td>– 1 mi in to race:</td>
</tr>
<tr>
<td>Baptism</td>
<td>Confirmation</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>H.S. – someone fr Yng Life</td>
<td>talked to him; he went back to church;</td>
</tr>
<tr>
<td></td>
<td>From this, he learned Christ</td>
</tr>
<tr>
<td></td>
<td>accepts mom.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>FUTURE: will meet the path (will continue to better self and accept mom like Christ accepts her)</td>
<td></td>
</tr>
<tr>
<td><strong>Denali</strong></td>
<td></td>
</tr>
<tr>
<td>Intro to God: Catholic Church</td>
<td>– H.S. Questioned beliefs (when found out mom had a mental illness)</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Lindsey</td>
<td>Growing up: Not many religious influences (Mom not religious)</td>
</tr>
<tr>
<td>---------</td>
<td>------------------------------------------------------------------</td>
</tr>
<tr>
<td>Julie</td>
<td>Faith Journey: A Movie</td>
</tr>
<tr>
<td></td>
<td>Beginning of movie: Believed in God: no struggle</td>
</tr>
<tr>
<td>Steph</td>
<td>Faith Journey: All of Life is a Journey</td>
</tr>
<tr>
<td></td>
<td>Younger: turned to God in prayer to help w/parent’s mental illnesses</td>
</tr>
<tr>
<td>Kelly</td>
<td>Faith Journey: Going through Different Parts of the Country</td>
</tr>
<tr>
<td></td>
<td>Plains: “real easy”</td>
</tr>
</tbody>
</table>

*Bolded words: aspects of the faith journey related to parent’s mental illness

* O = neutral/start of journey; + = movement toward the sacred; - = spiritual struggle (movement away from sacred)
## APPENDIX I

### EXEMPLARY QUOTES OF PARTICIPANTS’ SPIRITUAL STRUGGLE

<table>
<thead>
<tr>
<th>Loss Group</th>
<th>Participants</th>
<th>Exemplar Quotes – Spiritual Struggle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small</td>
<td>Billy</td>
<td>No spiritual struggle: “I guess I don’t really have any questions…It never was really, really prominent in my life.”</td>
</tr>
</tbody>
</table>
| Small      | Rachel       | Interpersonal – “My mom became more religious after my father died and she had depression. And there’s been a lot of tension between me and my mom because she wants me to go to Mormon church regularly, she wants me to go to the Mormon church here while I’m at school. She wants me to take part in sacraments. She wants me to do this, and that, and I don’t like being forced to do things that I’m not sure about. …I’m not going to be forced into a religion that I’m not sure I believe in. I don’t want to commit to something that huge that I’m not sure of. So there’s been a lot of tension in my family about that, because my mom and my sister are the active Mormons in my family.”

Divine/Intrapersonal – “I was just mad. I was so mad because I couldn’t understand why. I couldn’t understand why my dad had to die, why my mom almost died… And I was just mad that I had to deal with it. And I was mad that it didn’t happen later, or earlier, where I’d be too young to have to do anything about it. And I prayed, but it would be angry. I’d be scolding God, while I’m praying. And I’d just be so frustrated, and angry.” |
| Small      | Kevin        | Intrapersonal – “Maybe being angry at myself for being angry at her [mom]. Knowing that I’m not a disciple because I feel like those are people who are also really, really high up, but I’m trying to be a man of Christ so, I feel bad if I get mad at her, or anyone, but her in particular.” |
| Small      | Jackson      | Interpersonal – “The Catholic church used to teach…that if you commit suicide you’ll automatically go to Hell. And I just don’t agree with that. It’s something they can’t really help. I mean they’re really suffering…Anybody who goes through that much suffering – how can you say they weren’t justified? I think any God that just automatically damn somebody to Hell because they killed themselves or because they were really depressed is not really that merciful of a God. I just don’t agree with that, spiritually.”

Interpersonal – “Seeing that organized religion like has that mindset [view on suicide], it really threw me away from it. I just thought, ‘Why can’t I just worship God by myself and just take my own view on things, on what I believe is right?’ …It’s more correct in God’s eye to follow your own conscience than it is to follow the doctrine of the church…I believe the conscience is closer to God.” |
| Small      | Denali       | Intrapersonal – “I went through a really long period of questioning, especially through that time (middle school; finding out about mom’s illness), which is really interesting when I think about it.” |
| Large      | Lindsey      | Intrapersonal/Interpersonal – “After she went off of her medication, I went through a period where I actually lost a lot of connection with it, and I’m still trying to find it. For some reason, her views changed after she got off the medication, which was really odd of me. She’d been teaching me a certain way for so long, and then it completely, drastically changed.”

Divine – It gets harder to pray about it [mom’s illness] because…I’m not getting answers for it. So, it’s harder to constantly be coming up against this—the same thing—and then not getting answers.” |
| Large | Julie | Intrapersonal – “I was talking to people who did not believe in God, and again, my mom wasn’t getting better. My mom would say she looked to God for help, she prayed to God. So my thought was she’s praying…trying to get help from God, but she’s not getting better. Nothing’s happening. Eventually, I started to think in my head well, He must not exist…nothing good is happening.”

Interpersonal – “We would argue, you know, ‘If God’s so great, why hasn’t he helped you?’ And my mom would always be like, ‘He will.’ And I would be like ‘Well, when?’ And we would just argue about stuff like that and I would tell my mom…that God isn’t real cause he doesn’t do anything.”

Interpersonal – “…when I came to realize that my mom wasn’t going to get better anytime soon, I started to not believe in God…growing up, having the faith in my mom, and trying the best I can to have my faith in God, definitely hand-in-hand.”

Divine – “If God is omnipotent and great, why would he do this to my mom, why would he do this to me, why isn’t he helping me? Why isn’t he offering us any help? Everyone talked about how great God was and whatnot, but I just had never really personally saw that work in my life.”

Divine – “[To God:] ‘You supposedly do all these great things for all these people, who are good people. I feel like I’m a good person…I’m not getting anything out of this.’ So it usually had me feeling almost helpless…It was like, why even bother?”

| Large | Kelly | Intrapersonal – “[crying] I’ve wanted to go to church for a long time, and I just couldn’t get myself there. I couldn’t bring up my nerve to get into a church without breaking down. I feel like I would go into a church and start crying and people would be looking at me like I’m going crazy.”

Intrapersonal – “I don’t know what to believe. I’m just so confused right now I can’t put it into one category. I just, it was such a frustrating time in my life that I didn’t know what to believe or who to believe.”

Intrapersonal – “Everybody told me to turn to God and I tried…I just found that it didn’t make me feel any better…How could some…Being that controls all of our lives just take someone so important to me away from me? And so, I just stopped believing…it just wasn’t fair to me to lose somebody that important in my life…I didn’t go to church, I didn’t talk about God for like 2 years…”

Interpersonal – “[to the priest] I was like, “You don’t know what you’re talking about. You’ve never been through what I’m going through.” So that was just the final breaking point--when somebody told me I had to go [to church] to make myself feel better.”

Divine – “I wanted to believe that God did it for a reason but, the only reason I could think of was to hurt me. So, didn’t want to be religious anymore. I just wanted to forget what my dad [and mom] raised me to believe. It just was hard for me to go back and believe that it was ok for Him to do that.”

Divine – “When he first got sick I would pray every single day that he would get better and I would just pray that God would hear me and he’ll get better. I prayed every day for probably six straight months, and then he just kept getting worse. So, I prayed a little less and prayed for different things. When he had organ failure I just stopped praying all together.”

| Large | Steph | Intrapersonal – “I see it my mother doing everything possible she can, great woman, looking up to God for help and trying…just turning to Him and hoping, ‘Just give me a break, you know?’…And it hasn’t yet happened, so that’s really made turn away from God because I just don’t understand why someone’s life has to be so horrible, and they don’t do anything to deserve it…Was she put on earth just to be set an example of someone that just had a crappy life?”
Intrapersonal – “Because of seeing everything that my dad’s going through, and my mom, I would say if those things never had occurred and my parents weren’t ill, then I would probably have a great religious view on things…. But since it’s not like that, it’s made me turn away more because it’s got me thinking about things more and trying to understand them more, which normally wouldn’t have occurred if things were normal.”

Interpersonal – “I feel like the church just kinda turned their back on him because like we weren’t giving them money, and we weren’t making donations and stuff. We didn’t have that stone on the wall that has your name [that] you donated.”

Interpersonal – “…to have a church judge you like that and turn their back on you…they were fake to me and, you know, …they’ll go through life and if that’s what their going to do. they’ll have to deal with it later…But it was just kinda hard to believe that the church can be so much about money and politics…normally when you think of a church, you think you’re going to something deep, and they reach out and they help you to get through that bad time. And I don’t feel like they did that at all.”

Divine – [Regarding her relationship with God]: “Loss, for the most part because I was always raised with that belief…always thinking He’s there, and now…it’s kind of like a shock because you don’t really know if He is or not. And that could be just because I don’t believe and I don’t have faith…it could be my own fault.”
# Appendix J

**Exemplar Quotes of the Impact of Coping with a Parent with Mental Illness**

<table>
<thead>
<tr>
<th>Loss Group</th>
<th>Impact – Exemplar Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Small</strong></td>
<td></td>
</tr>
<tr>
<td>Billy</td>
<td>Emotionally – “I feel like it helped me to deal with a lot of different situations and just to know on my own personal level that how bad I’m feeling or how bad a situation is, it’s like I am able to keep it in perspective now, cause I can relate it back to that one time when I was at rock bottom and like, wow, it wasn’t really that bad. I can deal with this easily.”</td>
</tr>
<tr>
<td>Rachel</td>
<td>Limitation – “I’m very emotionally closed to people because I just want them to see the happy me. I don’t want to be my mom, and I’m just used to making her feel better, and not showing how I feel.”</td>
</tr>
<tr>
<td></td>
<td>Strength – “I’m also stronger because…I’ve had to deal with that, and I feel like I’m more mature than a lot of people my age. I matured very quickly (laughs) when I was younger, because I’d had to go through so many things at a young age.”</td>
</tr>
<tr>
<td>Kevin</td>
<td>Strength – “I’m stronger than most people mentally and emotionally, because of what I’ve been through.”</td>
</tr>
<tr>
<td>Jackson</td>
<td>Strength – “I’m a stronger individual for being able to deal with this and not being able to have some negative stereotype about people who have an illness…because I know how it is, and I know people who’ve had it and I think it makes me a stronger individual because that doesn’t make any difference to me, so.”</td>
</tr>
<tr>
<td>Denali</td>
<td>Views on Marriage and Family – For a while, I think I was seeing this strain that it [mom’s illness] put on my parent’s relationship. I mean that was a really rough three years. I know they would fight a lot…my dad…wanted to help my mom, but I don’t think he understood the situation fully…I remember for part of my life I was just like, I never want to get married. I’ll probably end up marrying someone like my dad, or someone like crazy…and then it was also, if I get married and have kids, are my kids gonna be like that? So, you know…I didn’t want any part of it…And now my attitude’s completely changed…I want to get married and have my own kids.”</td>
</tr>
<tr>
<td><strong>Large</strong></td>
<td></td>
</tr>
<tr>
<td>Lindsey</td>
<td>Relationships with others – “I am more conscious about other people now…especially what I do with other people. So I feel like the relationships that I do have with people, I really work on, or if I do make a mistake, I really apologize for it, and try to fix whatever I did. And I try to listen more now.”</td>
</tr>
<tr>
<td></td>
<td>Views on marriage and family – “That’s really up in the air right now, just because…before I was very set on having a husband and having kids, and with everything that has happened with my mom, especially after the depression, it seems like…I’m very scared of getting involved with somebody that I could possibly have a family with.”</td>
</tr>
<tr>
<td>Julie</td>
<td>Views on marriage and family – “For awhile I didn’t want kids – not at this point. I do want to get married, and I do want to have kids, but I want to do it later in life. Because…my mom and dad aren’t…as close as they used to be because of my mom’s drinking. She’s so distracted by it that they don’t go out and do anything together…I guess it just scared me seeing…my parents like that…I don’t want a marriage like that.”</td>
</tr>
<tr>
<td>Kelly</td>
<td>Strengths –“I’m not trying to brag, but I’ve been through a lot and I can deal with a lot more than what some people can. I’ve been through hell and back. I’m sure worse could happen, but I’ve been through tough spots in my life and it can only go up form here. So it just made me stronger in that way.”</td>
</tr>
<tr>
<td>Steph</td>
<td>Views on marriage and family – “I don’t want anything to do with a relationship or getting married or having kids because I realized I need to get my crap together before I can even do anything like that. So, I mean I’m not…turning all of it down but right now I don’t really…I just don’t even want to deal with that on top of everything else.”</td>
</tr>
</tbody>
</table>
Current Measures of Spiritual Struggle

The Negative Religious Coping subscale (NRCOPE) of Pargament’s Religious Coping Scale (RCOPE) has been used a great deal to measure spiritual struggle (Pargament, Koenig, Tarakeshwar & Hahn, 2004; Pargament, Magyar, Benore, & Mahoney, 2005; Pargament, Smith, Koenig, & Perez, 1998). Pargament, Smith, Koenig, and Perez (1998) define negative religious coping as a less mature relationship with God, manifested by a struggle in the search for significance.

The NRCOPE consists of 35 items and is divided into seven categories: Punishing God Reappraisal, Demonic Reappraisal, Reappraisal of God’s Power, Passive Religious Deferral, Pleading for Direct Intercession, Spiritual Discontent, and Interpersonal Religious Discontent. Refer to Table 1 within this Appendix for a list of the subscales of the NRCOPE, as well as accompanying definitions and individual subscale items.

Another measurement tool of spiritual struggle is the Religious Red Flags scale (Pargament, et al., 1998). The Religious Red Flags scale consists of three dimensions of ineffective types of religious coping and has been used to serve as religious “warning signs” – Wrong Direction, Wrong Road, and Against the Wind. Refer to Table 2 within this Appendix for a list of subscales of the Red Flags Scale, as well as accompanying definitions and individual subscale items.

Data Reduction and Theming

In order to assess the extent to which participants’ responses of spiritual struggle mapped onto the existing measures of spiritual struggle (e.g., the NRCOPE, Religious Red Flags), participants’ spiritual struggles were catalogued and grouped according to the three domains of spiritual struggle – interpersonal, intrapersonal, and Divine. After this initial grouping, participants’ responses were then matched with various subscales of the NRCOPE and the Religious Red Flags scales, according to the definitions and individual items of these subscales. Spiritual struggles that did not correspond to existing definitions and individual items were grouped separately, according to the three domains of spiritual struggle – interpersonal, intrapersonal, and Divine.

Preliminary Data Analysis

Below is a preliminary look at the degree to which participants’ responses of spiritual struggle map onto the current measures of spiritual struggle (e.g., NRCOPE, Religious Red Flags). Refer to Tables 3a, 3b, and 3c for participants’ responses grouped according to the NRCOPE and Religious Red Flags scales, as well as by spiritual struggle domain – Divine, interpersonal, and intrapersonal, respectively. Some of the subscales of the NRCOPE closely correspond to subscales of the Religious Red Flags scales. When this
is the case, both of the subscales are highlighted as representative of participants’ responses of spiritual struggle.

In order to give useful information about the spiritual struggles that correspond to each of the measures, various percentages are provided. First, the percentage of participants reporting spiritual struggles that map onto various spiritual struggle subscales within a particular domain is provided. Additionally, the percentage of participant responses that map directly onto existing subscales within a particular spiritual struggle domain (inter, intra, Divine) is provided. Participant responses are defined as the number of spiritual struggles reported by participants within a particular domain or subscale.

The percentage of participants reporting spiritual struggles within a particular spiritual struggle domain that do not map directly onto the various measures is also provided. Lastly, the percentage of participant responses within a particular domain that do not map directly onto various measures is provided.

**Spiritual Struggle with the Divine**

In Table 3a, participants’ spiritual struggles with the Divine are catalogued and mapped according to the NRCOPE and Religious Red Flags scales. The NRCOPE subscales that capture the participants’ responses include Punishing God Reappraisal and Spiritual Discontent. These NRCOPE subscales also closely correspond to two Religious Red Flags subscales – God’s Punishment and Anger at God. Ten percent of participants reported a Punishing God (NRCOPE)/God’s Punishment (Religious Red Flags) spiritual struggle, and 90% of participants endorsed Spiritual Discontent (NRCOPE)/Anger at God (Religious Red Flags) spiritual struggles. These spiritual struggles include 94% of participant responses in this domain (spiritual struggle with the Divine).

What is not captured by these two measures as it relates to spiritual struggle with the Divine, however, were participant reports of feeling selfish for praying for a parent and an inability to trust God. These responses were endorsed by 20% of participants.

**Interpersonal Spiritual Struggle**

In Table 3b, participants’ interpersonal spiritual struggles are catalogued and mapped according to the NRCOPE and Religious Red Flags scales. The NRCOPE subscale that captures participants’ responses in this domain is the Interpersonal Religious Discontent subscale. This NRCOPE subscale closely corresponds to the Religious Red Flags scale, Conflict with Church Dogma. As seen in the table, 40% of participants endorsed spiritual struggles that could be mapped onto this subscale.

Within the interpersonal spiritual struggle domain, however, 68% of responses within this domain are not captured by the NRCOPE. First, participants’ responses regarding family conflict about spiritual matters are currently not captured by this scale. Fifty percent of participants mentioned conflict with a family member over religious matters as it relates to their parent’s mental illness (e.g., arguing with the ill parent over God’s ability to help the parent). It is worth noting, however, that all of these items are captured by the Religious Red Flags subscale, Interpersonal Religious Conflict, which primarily encompasses religious conflict with family, friends, and church members.
There are also participant responses that are not captured by either the NRCOPE or the Religious Red Flags scales. These responses fall into themes, such as feeling that the church is judgmental and fake, feeling that the church doesn’t understand various issues related to mental illness, feeling as though one doesn’t “fit in” at church, fear of expressing one’s opinions in church, and losing faith in a trusted spiritual guide. Sixty percent of participants mentioned an interpersonal spiritual struggle as it relates to at least one of these 5 themes.

Intrapersonal Spiritual Struggle

In Table 3c, participants’ intrapersonal spiritual struggles are catalogued and mapped according to the NRCOPE and Religious Red Flags scales. It is interesting to note that none of these responses map directly onto the NRCOPE, but are mentioned by 90% of participants. Some of these responses, however, are captured by the Religious Red Flags subscale, Religious Doubts. Such responses were mentioned by 90% of participants and include questions about the parent’s mental illness, questions about the participant’s situation in coping with a parent with mental illness, as well as general confusion and doubt about one’s religious/spiritual beliefs.

There are also participant responses that do not map directly onto either the NRCOPE or the Religious Red Flags scale. These items are endorsed by 40% of participants and include responses such as emotions not captured by the scales (e.g., sadness, anxiety, disappointment, regret, and curiosity), as well as participants’ mention of feeling guilt for struggling with his/her spirituality/religiousness (e.g., wondering if it’s her fault that she doesn’t feel God’s presence; feeling guilty for feeling angry at God).

Conclusion

The NRCOPE and Religious Red Flags scales capture many elements of spiritual struggle. However, present findings suggest elements in the three domains of spiritual struggle not included in these measures. Within the spiritual struggle with the Divine domain, issues of losing trust/feeling selfish as it relates to God were reported by participants. In terms of interpersonal spiritual struggle, issues of family/friend conflict over religious matters, as well as elements related to the church (i.e., regarding the church as judgmental/fake, fear of expressing one’s opinion in church) were not present in the NRCOPE. Various issues of intrapersonal spiritual struggle reported by participants were not present in the NRCOPE, including issues surrounding religious questions/confusion/doubt, as well as various emotions, such as sadness, anxiety, disappointment, regret, curiosity, and guilt. It should be noted that these analyses are preliminary and further analyses are planned.
Table 1 (Appendix K): Subscales of the NRCOPE and their definitions and individual items

<table>
<thead>
<tr>
<th>NRCOPE Subscale</th>
<th>Subscale Items</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Punishing God</strong></td>
<td></td>
</tr>
<tr>
<td>Reappraisal:</td>
<td></td>
</tr>
<tr>
<td>Redefining the stressor as a punishment from God for the individual’s sins</td>
<td>Wondered whether God was punishing me because of my lack of faith.</td>
</tr>
<tr>
<td></td>
<td>Decided that God was punishing me for my sins.</td>
</tr>
<tr>
<td></td>
<td>Felt punished by God for my lack of devotion.</td>
</tr>
<tr>
<td></td>
<td>Wondered if God allowed this event to happen to me because of my sins.</td>
</tr>
<tr>
<td></td>
<td>Wondered what I did for God to punish me.</td>
</tr>
<tr>
<td><strong>Demonic Reappraisal:</strong></td>
<td></td>
</tr>
<tr>
<td>Redefining the stressor as the act of the Devil</td>
<td>Believed the devil was responsible for my situation.</td>
</tr>
<tr>
<td></td>
<td>Felt the situation was the work of the devil.</td>
</tr>
<tr>
<td></td>
<td>Felt the devil was trying to turn me away from God.</td>
</tr>
<tr>
<td></td>
<td>Decided the devil made this happen.</td>
</tr>
<tr>
<td></td>
<td>Wondered if the devil had anything to do with this situation.</td>
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<tr>
<td><strong>Reappraisal of God’s Power:</strong></td>
<td></td>
</tr>
<tr>
<td>Redefining God’s power to influence the stressful situation</td>
<td>Felt that even God has limits.</td>
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<tr>
<td></td>
<td>Realized there were some things that even God could not change.</td>
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<tr>
<td></td>
<td>Realized that God cannot answer all of my prayers.</td>
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<tr>
<td></td>
<td>Thought that some things are beyond God’s control.</td>
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<tr>
<td><strong>Passive Religious Deferral:</strong></td>
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</tr>
<tr>
<td>Passive waiting for God to control the situation</td>
<td>Didn’t try much of anything; simply expected God to take control.</td>
</tr>
<tr>
<td></td>
<td>Knew that I could handle the situation, so I just expected God to handle it for me.</td>
</tr>
<tr>
<td></td>
<td>Didn’t try to do much; just assumed God would handle it.</td>
</tr>
<tr>
<td></td>
<td>Didn’t do much; just expected God to solve my problem for me.</td>
</tr>
<tr>
<td><strong>Pleading for Direct Intercession:</strong></td>
<td></td>
</tr>
<tr>
<td>Seeking control indirectly by pleading to God for a miracle of divine intercession</td>
<td>Pleased with God to make everything work out.</td>
</tr>
<tr>
<td></td>
<td>Prayed for a miracle.</td>
</tr>
<tr>
<td></td>
<td>Made a deal with God so that He would make things better.</td>
</tr>
<tr>
<td></td>
<td>Pleased with God to make things turn out OK.</td>
</tr>
<tr>
<td></td>
<td>Bargained with God to make it better.</td>
</tr>
<tr>
<td><strong>Spiritual Discontent:</strong></td>
<td></td>
</tr>
<tr>
<td>Experiencing confusion and dissatisfaction with God’s relationship to the individual in the stressful situation</td>
<td>Questioned the power of God.</td>
</tr>
<tr>
<td></td>
<td>Wondered whether God had abandoned me.</td>
</tr>
<tr>
<td></td>
<td>Felt angry that God was not there for me.</td>
</tr>
<tr>
<td></td>
<td>Wondered God’s love for me.</td>
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<tr>
<td></td>
<td>Wondered if God really cares.</td>
</tr>
<tr>
<td></td>
<td>Voiced anger that God didn’t answer my prayers.</td>
</tr>
<tr>
<td><strong>Interpersonal Religious Discontent:</strong></td>
<td></td>
</tr>
<tr>
<td>Expression confusion and dissatisfaction with the relationship of clergy or members to the individual in the stressful situation</td>
<td>Felt my church seemed to be rejecting or ignoring me.</td>
</tr>
<tr>
<td></td>
<td>Wondered whether my clergy was really there for me.</td>
</tr>
<tr>
<td></td>
<td>Wondered whether my church had abandoned me.</td>
</tr>
<tr>
<td></td>
<td>Disagreed with what the church wanted me to do or believe.</td>
</tr>
<tr>
<td></td>
<td>Felt dissatisfaction with the clergy.</td>
</tr>
<tr>
<td><strong>“Reverse”</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tried to deal with the situation on my own without God’s help.</td>
</tr>
<tr>
<td></td>
<td>Made decisions about what to do without God’s help.</td>
</tr>
<tr>
<td></td>
<td>Depended on my own strength without support from God.</td>
</tr>
</tbody>
</table>
### Religious Red Flags Scale

**Wrong Direction:** An imbalance between concerns with the self and concerns outside of the self.

#### Self Neglect
1. Decided to devote all of my time to my religion.
2. Realized that my own desires were trivial and that the only thing that counts is getting to heaven.
3. Decided to sacrifice my own interests and live only for God.
4. Decide to stop taking care of myself and focus only on what God wants for me.
5. Realized the world is not important to me and decided to spend all of my energies serving God.

#### Self Worship
1. Decided to turn away from God and live life for myself alone.
2. Realized that nothing counts in the world but me, not even God.
3. Decided to look out for myself alone and no longer worry about morality.
4. Decided to start caring about me and stop caring about God.
5. Decided to reject my religious beliefs and focus only on my own pleasures.

#### Religious Apathy
1. Lost interest in God, other people, myself, and everything else.
2. God showed me that life is pointless so I decided to give up trying.
3. Became fed up with God and the world and stopped caring about what happens.
4. Stopped caring after God showed me how futile life is.
5. Stopped caring about the things that were important to me—god, the church, myself.

**Wrong Road:** Religious coping strategies that are unsuitable reactions to various stressors.

#### God’s Punishment
1. Felt my lack of spirituality was responsible for the event.
2. Felt that I deserved to be punished by God for my bad thoughts or actions.
3. Felt the event was God’s way of telling me that I had failed Him.
4. Believed that God would not have let this happen unless I created or caused it.
5. Believed God was punishing me for my sins.

#### Religious Passivity
1. Surrendered to God’s will since nothing I could do would make a difference anyway.
2. Waited for a sign from God about what to do.
3. Let the church handle the situation for me.
4. Knew God would make the situation better if I just waited long enough.
5. Felt that without God I was totally helpless.

#### Religious Vengeance
1. Realized that God would punish true sinners.
2. Asked God to make others hurt so they would know how I feel.
3. Prayed that God would punish the real sinners.
4. Believed that God will have his vengeance on those who sin.

#### Religious Denial
1. Wasn’t upset because I believed this would bring me closer to God.
2. Refused to feel bad because my faith teaches that there is good in everything.
3. Wasn’t bothered at all because it was God’s will.
4. Wasn’t bothered at all because God has His own plan for things.

**Against the Wind:** Conflicts with other people, within oneself, and with God.

#### Interpersonal Religious Conflict
1. Family or friends spoke to me about religion in a way I didn’t agree with.
2. Argued with family or friends about faith, God, and religion.
3. Felt that the church did not support me in my time of need.
4. Felt angry that no church members comforted me.

#### Conflict with Church Dogma
1. Disagreed with my clergy about faith, God, and religion.
2. Disagreed with the way the church wanted me to handle my situation.
3. Disagreed with the church’s view that I should accept this suffering as part of my faith.
4. Disagreed with the way my clergy thought I should handle this situation.
5. Disagreed with the church’s view about why this event happened to me

#### Anger at God
1. Became angry with God who let bad things happen to good people.
2. Felt angry that God did not hear my prayers.
3. Felt surprised that the God I loved could be so cruel.
4. Felt God was not being fair to me.
5. Could not forgive God for letting this event happen.

#### Religious Doubts
1. Questioned whether god really exists.
2. Had doubts about my faith.
3. Felt that my whole religious approach to life was thrown into confusion.
4. Had difficulty gaining comfort from my religious beliefs.
5. Had doubts about my religious beliefs.
<table>
<thead>
<tr>
<th>Measurement Subscale</th>
<th>Participant Responses</th>
</tr>
</thead>
</table>
| **NRCOPE: Punishing God**
Reappraisal | |
| **Red Flags:** God’s Punishment
(Wrong Road) | Decided God did this to hurt her – Kelly |
| 10% of participants | |
| **NRCOPE: Spiritual Discontent** | QUESTIONS:
Religious questions: Why didn’t God show me what my father was doing wrong? – Scott
Is there a God? – Rachel, Denali
Is God listening? – Denali

Question about family hardship: Why isn’t He helping us? – Julie | Emotion toward God:
Frustratn – Scott, Kelly, Rachel, Jackson, Steph, Kevin, Denali
Anger – Kelly, Rachel, Scott
Enraged – Scott

Watched parent turn to God, in vain – Steph, Julie
Never Gotten Support from God – Steph
Turned away fr God (mom turning to God – not getting better)-Steph
I don’t hear/feel God - Julie
Felt Betrayed by God – Julie
Felt God didn’t love her - Julie
No help from God - Julie

Prayer:
Turned to God, but didn’t feel better – Kelly
Prayed, but dad got worse – Kelly, Julie
Scolded God in her prayers – Rachel
Harder to pray – not getting answers – Lindsey
Helped only in the short term, not the long term –Steph
Sometimes she would feel support, sometimes hopeless – Denali |
| 90% of participants | |
| Not captured by
NRCOPE or Religious Red Flags | **Prayer:** felt selfish for praying for one person – Kelly
Stopped trusting God – Julie |
| 20% of participants | = 1 participant response
= 31 participant responses
= 2 participant responses |
<table>
<thead>
<tr>
<th>Measurement Subscale</th>
<th>Participant Responses</th>
<th>Red Flags: Conflict with Church Dogma (Against the Wind)</th>
</tr>
</thead>
</table>
| **NRCOPE:** Interpersonal Religious Discontent  
40% of participants | * Pushed away people in church community who tried to get them to go back to church – Kelly  
* Disagreed with, and angry at, her priest, who told her to turn to God – Kelly  
* Angry about Catholic Church’s stance on suicide – Jackson  
* Feels abandoned by church – Steph  
* Didn’t feel support from religious community – Scott | * No church community support in dealing with parent’s mental illness – Scott, Steph  
* Felt the church community didn’t support him during what he went going through – Scott  
* Felt abandoned by the church (lost frnds, dad didn’t receive supprt) – Steph  
* Feels abandoned by church community – Steph  

= 9 participant responses |
| **NRCOPE:** None  
50% of participants | FAMILY CONFLICT:  
* Mom became more religious after dx of mental illness; urged Rachel to be more religious: tension between she and mom; made her feel lost – Rachel  
* Aunt w/ same view on suicide, makes him angry – Jackson  
* Julie would argue with her mother because she didn’t believe that God would help her mother; her mother believed that God would help – Julie  
* Lost her faith in God when she lost her faith in mom – Julie | * Argmnts w/ mother when participant stopped going to church - Steph  
* Lost friends at church school when they found out about dad’s illness – Steph  
* Father did “disgusting things” as a pastor; hard to understand why dad did what he did – Scott  
* Felt lost because father had been spir guidance – Scott  

= 7 participant responses |
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not captured by NRCOPE or Religious Red Flags Scales</td>
<td>60% of participants</td>
</tr>
</tbody>
</table>
| CHURCH = JUDGMENTAL/FAKE:                     | * Felt the church was judgmental and fake – upset that the church wouldn’t support her dad because they couldn’t donate money – Steph  
* Church’s stance on suicide – Jackson                                                                                                             |
| CHURCH – DOESN’T UNDERSTAND                  | * Religious community didn’t understand what he was going through – Scott  
* Church doesn’t understand what it’s like to be suicidal – Jackson                                                                             |
| FEAR:                                        | * Afraid to express his opinion in church – Jackson  
* Afraid what they’ll think – mental illness or suicidal? – Jackson                                                                               |
| DON'T FIT N:                                  | * Felt like she didn’t fit in, even though she wanted to be involved – Denali                                                                       |
| LOST FAITH IN TRUSTED SPirit GUIDE:          | * Lost faith in god when she lost faith in her mother – Julie  
* Felt he lost his spiritual guide after finding out what his father had done – Scott  
* After diagnosis, mom became more religious: felt lost – Rachel  
* After going off medication, mom became more religious: felt lost – Lindsey                                                                         |

= 12 participant responses
### Table 3c (Appendix K): Participants’ reports of intrapersonal spiritual struggle mapped onto the NRCOPE and Religious Red Flags

<table>
<thead>
<tr>
<th>NRCOPE: None</th>
<th>Questions about parent’s illness:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Red Flags: Religious Doubts</td>
<td>Why did s/he have to be this way? – Kelly, Julie, Rachel, Denali</td>
</tr>
<tr>
<td>90% of participants</td>
<td>Why does she have to be mean? – Kevin</td>
</tr>
<tr>
<td></td>
<td>Why would he take someone away? – Kelly</td>
</tr>
<tr>
<td></td>
<td>Why does she have to be depressed? – Denali</td>
</tr>
<tr>
<td></td>
<td>Does she care? – Denali</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Questions about participant’s situation:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Why do I have to take care of her? – Rachel, Denali</td>
</tr>
<tr>
<td>Why does my situation have to be this way? – Jackson, Julie, Denali</td>
</tr>
<tr>
<td>Would God do that to me? – Rachel, Denali</td>
</tr>
<tr>
<td>What’s the point if I’m going to end up like my father? – Scott</td>
</tr>
<tr>
<td>Why did I have to grow up so fast (to take care of my family)? – Denali</td>
</tr>
<tr>
<td>Why is my day different than my friends? – Denali</td>
</tr>
<tr>
<td>Why does something bad have to happen to a good person? – Rachel</td>
</tr>
<tr>
<td>Why does anyone have to have it? – Kevin</td>
</tr>
<tr>
<td>Why would God do that to someone? – Kevin, Steph, Denali</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Questions about belief system:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does my belief system matter? – Denali</td>
</tr>
<tr>
<td>What happens when you die? – Denali</td>
</tr>
<tr>
<td>If something good happens, is that fate? – Denali</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emotions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sadness – Lindsey, Steph</td>
</tr>
<tr>
<td>Anxiety – Steph</td>
</tr>
<tr>
<td>Disappointment – Steph</td>
</tr>
<tr>
<td>Regret – Steph</td>
</tr>
<tr>
<td>Curiosity – Denali</td>
</tr>
<tr>
<td>Emotional rollercoaster – Scott</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Guilt:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wonders if it’s her own fault that she doesn’t feel God’s presence &amp; has lost her faith – Steph</td>
</tr>
<tr>
<td>Doesn’t feel God’s presence – is it wrong that I’m not turning to God? – Steph</td>
</tr>
<tr>
<td>Anger at God - felt guilty for feeling enraged – am I burning a bridge? Am I sinning? – Scott</td>
</tr>
<tr>
<td>Religious doubt – fear that there were consequences for doubting God/religion – Scott</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not captured by NRCOPE or Religious Red Flags</th>
<th>= 40 participant responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>40% of participants</td>
<td>Confused about belief – Kelly, Lindsey</td>
</tr>
<tr>
<td></td>
<td>Feels Lost Spiritually – Lindsey, Steph, Denali, Scott</td>
</tr>
<tr>
<td></td>
<td>Wished Religion would be more of a comfort – Rachel</td>
</tr>
<tr>
<td></td>
<td>Felt Religion was a Mind Game, a Trick – Steph, Julie</td>
</tr>
<tr>
<td></td>
<td>Stopped believing for some time – Jackson, Julie, Lindsey, Kelly</td>
</tr>
<tr>
<td></td>
<td>Couldn’t find peace through religion – Scott</td>
</tr>
</tbody>
</table>

| = 11 participant responses |
### Table 1: Participant demographics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Religious Affil</th>
<th>Freq: Church Attendance</th>
<th>Overall religiousness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Billy</td>
<td>18</td>
<td>M</td>
<td>None</td>
<td>Never</td>
<td>3</td>
</tr>
<tr>
<td>Rachel</td>
<td>20</td>
<td>F</td>
<td>Non-Denom Christian</td>
<td>Few times/year</td>
<td>2</td>
</tr>
<tr>
<td>Kevin</td>
<td>20</td>
<td>M</td>
<td>Lutheran</td>
<td>Few times/month</td>
<td>3.5</td>
</tr>
<tr>
<td>Jackson</td>
<td>19</td>
<td>M</td>
<td>Catholic</td>
<td>Once a month</td>
<td>4</td>
</tr>
<tr>
<td>Denali</td>
<td>20</td>
<td>F</td>
<td>Non-Denom Christian</td>
<td>Once a week</td>
<td>2</td>
</tr>
<tr>
<td>Lindsey</td>
<td>22</td>
<td>F</td>
<td>Catholic</td>
<td>Once a week</td>
<td>2</td>
</tr>
<tr>
<td>Julie</td>
<td>19</td>
<td>F</td>
<td>Agnostic</td>
<td>Never</td>
<td>2</td>
</tr>
<tr>
<td>Kelly</td>
<td>19</td>
<td>F</td>
<td>Catholic</td>
<td>Never</td>
<td>2</td>
</tr>
<tr>
<td>Steph</td>
<td>22</td>
<td>F</td>
<td>Catholic</td>
<td>Few time/year</td>
<td>2</td>
</tr>
</tbody>
</table>
Table 2: Characteristics of Parents’ Mental Illness

<table>
<thead>
<tr>
<th>Participant</th>
<th>Parent’s Dx</th>
<th>Age Parent Given Dx</th>
<th>Age Participant Learned of Dx</th>
<th>Hospitalized</th>
<th>Last Hosp</th>
</tr>
</thead>
<tbody>
<tr>
<td>Billy</td>
<td>Mom: PTSD/depression Dad: anxiety/depression</td>
<td>Late 20s</td>
<td>Childhood</td>
<td>No</td>
<td>NA</td>
</tr>
<tr>
<td>Rachel</td>
<td>Mom: depression</td>
<td>54</td>
<td>Adolescence</td>
<td>No</td>
<td>NA</td>
</tr>
<tr>
<td>Jackson</td>
<td>Dad: depress, OCD, SAD Mom: anxiety</td>
<td>Dad: early 20s Dad: DK Mom: Adolescence Dad: Childhood</td>
<td>No</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>Kevin</td>
<td>Mom: bipolar disorder</td>
<td>DK</td>
<td>Childhood</td>
<td>No: refuses</td>
<td>NA</td>
</tr>
<tr>
<td>Denali</td>
<td>Mom: depression, cyclomania</td>
<td>30s</td>
<td>Adolescence</td>
<td>No</td>
<td>NA</td>
</tr>
<tr>
<td>Kelly</td>
<td>Dad: depression/alcohol</td>
<td>36</td>
<td>Adolescence</td>
<td>No</td>
<td>NA</td>
</tr>
<tr>
<td>Lindsey</td>
<td>Mom: depression</td>
<td>42</td>
<td>Adolescence</td>
<td>No</td>
<td>NA</td>
</tr>
<tr>
<td>Julie</td>
<td>Mom: depress, alcohol</td>
<td>DK</td>
<td>Adolescence</td>
<td>1 hosp 1 rehab</td>
<td>Hospital: April 06</td>
</tr>
<tr>
<td>Steph</td>
<td>Mom: depression Dad: depression, bipolar disorder</td>
<td>Mom: 42 Dad: 49</td>
<td>Mom: Adulthood Dad: Childhood</td>
<td>Mom: no Dad: 4 times</td>
<td>Dec 2004</td>
</tr>
</tbody>
</table>
Table 3: Categories of loss endorsed by each participant

<table>
<thead>
<tr>
<th>Participant</th>
<th>Loss Categories Endorsed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Billy</td>
<td>Loss of roles of mother, father, child</td>
</tr>
<tr>
<td></td>
<td>Loss or worry about future</td>
</tr>
<tr>
<td></td>
<td><em>Billy</em> – “I worry that he’s not going to be around through both of my brothers’ high school years, and this may seem selfish, but I don’t wanna have to let go of my goals and dreams and stuff to come back and have to help out there.” (Worry about the future)</td>
</tr>
<tr>
<td>Rachel</td>
<td>Loss of roles of mother, father, child</td>
</tr>
<tr>
<td></td>
<td>Loss of routine</td>
</tr>
<tr>
<td></td>
<td><em>Rachel</em> – “I felt like I was my mom’s mother a lot of the time. She sleeps all day on the weekends, so I’d go in and try to get her out of bed. [I’d do] things for her—I’d go to the grocery store for her, make sure she’s taking her medicines. She would always sleep with the T.V. on, and I’d always go in and turn it off after she falls asleep.” (Loss of roles of mother, father, or child)</td>
</tr>
<tr>
<td>Kevin</td>
<td>Loss of roles of mother, father, child</td>
</tr>
<tr>
<td></td>
<td>Loss of relationships with others</td>
</tr>
<tr>
<td></td>
<td><em>Kevin</em> – “Everyone always thinks the mom is the one you wanna go to if you’re sad…The dad is the strict person, but my dad had to play both a lot. But my mom was still a mom and she wasn’t always in a bad attitude. But, it kind of took away from the stereotypical mom, dad—who you want to go to for a certain situation” (Loss of roles of mother, father, or child)</td>
</tr>
<tr>
<td>Jackson</td>
<td>Loss or worry about future</td>
</tr>
<tr>
<td></td>
<td><em>Jackson</em> – “I worry about what would happen to my dad a lot – how I would deal with that, how it would affect our family…with either parent I worry about how will it affect my future. Especially if something happened to them tomorrow – I’ve still got a brother in high school and a sister in junior high. And that would just completely alter my life… if something happened to them, like right now, I would have to drop out of college.” (Worry about the future)</td>
</tr>
<tr>
<td>Denali</td>
<td>Loss of roles of mother, father, child</td>
</tr>
<tr>
<td></td>
<td>Loss of a sense of self</td>
</tr>
<tr>
<td></td>
<td>Loss of routine</td>
</tr>
<tr>
<td></td>
<td><em>Denali</em> – “When my mom was on medication she was always asleep and I’d always go in and remind my brother to take his medicine. I was like the mom. And then I’d have to go remind my dad to do stuff. It was really frustrating cause I was thirteen years old, and I’m trying to run this household and, no one would like take me seriously.” (Loss of roles of mother, father, or child)</td>
</tr>
<tr>
<td>Name</td>
<td>Loss of roles of mother, father, child</td>
</tr>
<tr>
<td>-------</td>
<td>--------------------------------------</td>
</tr>
<tr>
<td>Lindsey</td>
<td>“I’ve struggled with it a lot. There are many decisions that I would like to make and I can’t make them right now because I’m stuck in this limbo… I feel really tied to my mom right now because she doesn’t really have it under control yet. I can’t go off and make my own decisions like a lot of people… I’m just kind of stuck in the school position.”</td>
</tr>
<tr>
<td>Julie</td>
<td>“I worry that as she gets older, its [mother’s drinking problem] going to worsen and I don’t know if this is selfish but I feel like if her drinking becomes a serious problem, I’m going to have to put my life on hold to take care of her, or I’m going to constantly be worrying about her and I don’t want to do that. So I know that’s selfish but I just don’t want to have to worry about… that’s something that scares me about my future.”</td>
</tr>
<tr>
<td>Kelly</td>
<td>“It really is like losing somebody when my dad was battling depression… he wasn’t the same person anymore. I wouldn’t ever want that on anybody. I wouldn’t wish that on my worst enemy – for somebody’s parent to be like that.”</td>
</tr>
<tr>
<td>Steph</td>
<td>“Once I lost my dad, my mom kinda went along with him. So, it was kind of like you lost both parents at the same time… she’s constantly stressed out working to support us by herself. And as much as she wanted to be there for us, she just couldn’t. She could only do so much. It was just kinda like raising yourself.”</td>
</tr>
</tbody>
</table>
Table 4: Number of Participants Endorsing Each Loss of a Normal Life Category

<table>
<thead>
<tr>
<th>Loss Category</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of roles of mother, father, child</td>
<td>8</td>
</tr>
<tr>
<td>Loss or worry about future</td>
<td>6</td>
</tr>
<tr>
<td>Loss of a sense of self</td>
<td>5</td>
</tr>
<tr>
<td>Loss of routine</td>
<td>5</td>
</tr>
<tr>
<td>Loss of relationships with others</td>
<td>4</td>
</tr>
</tbody>
</table>
Table 5: Faith journey as a function of loss of a normal life

<table>
<thead>
<tr>
<th>Loss Category</th>
<th>Participants</th>
<th>Faith Journey</th>
</tr>
</thead>
</table>
| Small (1-3 Loss categories) | Billy, Rachel, Kevin, Jackson, Denali | **Content w/beliefs (even if they don’t know what they believe)**  
  *Billy* – Found a middle ground b/n belief/non-belief: OK w/current beliefs  
  *Rachel* – At peace, even though hasn’t decided on a religion  
  *Kevin* – Became more involved w/church & Young Life; OK with beliefs  
  *Jackson* – Catholic retreat; resolved spiritual struggle; Now: sure of beliefs; making sure they’re his beliefs, not someone else’s  
  *Denali* – Recently has felt her faith was ‘reaffirmed;’ trying to find belief system—ok with this; spiritual hunger |
| Large (4-5 Loss categories) | Lindsey, Julie, Kelly, Steph | **Lost; no spiritual direction**  
  *Lindsey* – Feels spiritually lost after mom went off medication and became more religious  
  *Julie* – Lost her faith – went hand-in-hand with losing faith in mother’s ability to stop drinking  
  *Kelly* – Just moving past feeling spiritually lost after father’s death; more of a religious center  
  *Steph* – Spiritually lost – she and her mother turned to God, in vain; felt abandoned/judged by church |
Table 6: Spiritual struggles per person and loss group, catalogued according to spiritual struggle domains and loss groups

<table>
<thead>
<tr>
<th>Loss Group</th>
<th>Participant</th>
<th>Interpersonal S.S.</th>
<th>Intrapersonal S.S.</th>
<th>Divine S.S.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small</td>
<td>Billy</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Small</td>
<td>Rachel</td>
<td>Mom-more rel after diagnosis of mental illness – conflict b/n mom and Rachel</td>
<td>Questioned-why did this happen? Confused about what to believe Wishes religion was more of a comfort</td>
<td>Anger/frustration toward God (1yr) – Scold God while praying</td>
</tr>
<tr>
<td>Small</td>
<td>Kevin</td>
<td></td>
<td>Questioned-why did this happen? Personal doubt Angry @ self: not acting like Christ’s disciple</td>
<td>Frustration w/God</td>
</tr>
<tr>
<td>Small</td>
<td>Jackson</td>
<td>Catholic church’s stance on suicide Aunt w/similar views on suicide Afraid to express opinion to church – think he has m.i./suic</td>
<td>Questioned-why did this happen? Confused about what to believe</td>
<td>Frustration/blame God: “little bit”</td>
</tr>
<tr>
<td>Small</td>
<td>Denali</td>
<td>Didn’t feel like she fit in @ church.</td>
<td>Questioned religious beliefs Questioned-why did this happen?</td>
<td>Frustration/irritation w/God Didn’t feel strength/support fr God</td>
</tr>
<tr>
<td>Large</td>
<td>Lindsey</td>
<td>Mom-more rel after going of meds meds-confusing/conflict</td>
<td>Lost connection with spirituality Doesn’t know what to believe</td>
<td>Mad/blame God: initially Prays, but feels not getting ansrs</td>
</tr>
<tr>
<td>Large</td>
<td>Julie</td>
<td>Disagreed with mom’s belief that God was helping her.</td>
<td>Stopped believing-felt rel was a trick Questioned-why did this happen? Why me?</td>
<td>Never devlop relationship w/ God No help from God Felt betrayed by God Felt she couldn’t trust God Felt God didn’t love her Prayed – parent got worse</td>
</tr>
<tr>
<td>Large</td>
<td>Kelly</td>
<td>Unable to go into a church (2 yrs) – reminds of father’s funeral Conflict with church members who tried to get her to church Felt priest didn’t understand</td>
<td>Questioned – why did this happen? Confused – what to believe; stopped believing Frustration with God (2 yrs)</td>
<td>Turned to God, but didn’t feel better Frustration with God (2 yrs) Prayed to God, but dad got worse Decided God did it to hurt her Felt selfish for praying for dad</td>
</tr>
<tr>
<td>Large</td>
<td>Steph</td>
<td>Felt church turned back on her father and family (abandoned) Feels church is judgmental/fake Lost church school friends when found out about dad illness Argue w/mom about going to church Watched mother turn to God, in vain Stopped going to Catholic church – frustration w/ community</td>
<td>Questioned-why did this happen? Feels she has never felt support fr religion Feels religion is a mind game Confused about what to believe</td>
<td>Feels guilt – doesn’t have faith and isn’t turning to God Feels God’s not responding to her Turned away from God (noticed mom turning to God, but not getting better) Frustration/blame God</td>
</tr>
</tbody>
</table>
Table 7a: Number of spiritual struggles per person and number of spiritual struggle domains per person, as a function of Small Loss groups

<table>
<thead>
<tr>
<th>Loss Group</th>
<th>Participants</th>
<th>Number of spiritual struggles</th>
<th>Spiritual Struggle Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small</td>
<td>Billy</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Small</td>
<td>Rachel</td>
<td>Mom-more rel after diagnosis of mental illness – conflict b/n mom and Rachel Questioned-why did this happen? Confused about what to believe Wishes religion was more of a comfort Anger/frustration toward God – scold God while praying (1 yr) = 5</td>
<td>2-3 (Intra – brief)</td>
</tr>
<tr>
<td>Small</td>
<td>Kevin</td>
<td>Questioned-why did this happen? Personal doubt – for a split second Angry @ self for being angry at mom: feels he’s not acting like Christ’s disciple Frustration w/God – when younger = 4</td>
<td>1-2 (Intra – “split second”) (Divine – when younger)</td>
</tr>
<tr>
<td>Small</td>
<td>Jackson</td>
<td>Struggles with Catholic church’s stance on suicide (that they go to Hell) Struggles with aunt’s similar view on suicide Afraid to express opinion to church – they’ll think he has an illness/suicidal Questioned-why did this happen? Confused about what to believe – stopped believing for a time Frustration/blame God: “little bit” = 6</td>
<td>2-3 (Divine-“a little bit”)</td>
</tr>
<tr>
<td>Small</td>
<td>Denali</td>
<td>Didn’t feel like she fit in @ church Questioned religious beliefs – when younger Questioned-why did this happen? Frustration/irritation w/God – when younger Didn’t feel strength and support from God – when younger = 5</td>
<td>1-3 (Intra – when younger) (Divine – when younger)</td>
</tr>
<tr>
<td>Loss Group</td>
<td>Participants</td>
<td>Number of spiritual struggles</td>
<td>Spiritual Struggle Domains</td>
</tr>
<tr>
<td>------------</td>
<td>--------------</td>
<td>------------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>Large</td>
<td>Lindsey</td>
<td>Mom-more rel after going off medication - conflict b/n Lindsey and mom – confusing Questioned-why did this happen? Lost connection with spirituality Confused about what to believe Mad/blame God Prays, but feels she’s not getting answers</td>
<td>6</td>
</tr>
<tr>
<td>Large</td>
<td>Julie</td>
<td>Conflict with mom – disagreed that God was helping her mother Stopped believing – lost faith in God when lost faith in mom inability to get better Felt religion was a trick and that God didn’t exist Questioned-why did this happen? Why me? Never developed relationship with God – doesn’t feel or hear God No help from God Felt betrayed by God Felt she couldn’t trust God Felt God didn’t love her Prayed – parent got worse</td>
<td>10</td>
</tr>
<tr>
<td>Large</td>
<td>Kelly</td>
<td>Unable to go into a church (2 yrs) – reminds her of her father’s funeral Conflict with church members who tried to get her to church Felt priest didn’t understand Questioned – why did this happen? Confused about what to believe – stopped believing Turned to God, but didn’t feel better Frustration with God (2 yrs) Prayed to God, but didn’t get answers and dad got more sick Decided God took her father away to hurt her Felt selfish for praying just for dad</td>
<td>10</td>
</tr>
<tr>
<td>Large</td>
<td>Steph</td>
<td>Felt church turned back on her father and family (abandoned) Feels church is judgmental/fake Lost church school friends when found out about dad illness Argue w/mom about going to church Watched mother turn to God, in vain Stopped going to Catholic church because of frustration with church community Questioned-why did this happen? Feels she has never felt support fr religion Feels religion is a mind game Confused about what to believe Feels guilt that she doesn’t have faith and isn’t turning to God Feels God’s not responding to her Turned away from God (noticed mom turning to God, but not getting better) Frustration/blame God</td>
<td>14</td>
</tr>
<tr>
<td>Loss Group</td>
<td>Part</td>
<td>Changes</td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td>--------</td>
<td>-------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Small</td>
<td>Billy</td>
<td>NONE</td>
<td></td>
</tr>
<tr>
<td>Small</td>
<td>Rachel</td>
<td>POSITIVE and NEGATIVE: took something negative (mom’s illness/spiritual struggles) to make a positive (developing some religious views)</td>
<td></td>
</tr>
<tr>
<td>Small</td>
<td>Kevin</td>
<td>POSITIVE: spiritual struggle were initially a “downfall,” but they have made him a better person</td>
<td></td>
</tr>
<tr>
<td>Small</td>
<td>Jackson</td>
<td>POSITIVE: better person for having to deal with his spiritual struggles; proud of self for standing up for his belief system</td>
<td></td>
</tr>
<tr>
<td>Small</td>
<td>Denali</td>
<td>POSITIVE: made her appreciate things that were given to her (strengths and talents)</td>
<td></td>
</tr>
<tr>
<td>Large</td>
<td>Lindsey</td>
<td>POSITIVE and NEGATIVE: less connected with spirituality (negative), BUT will be able to prove to God she can find her way back (positive) (quote)</td>
<td></td>
</tr>
<tr>
<td>Large</td>
<td>Julie</td>
<td>POSITIVE and NEGATIVE: doesn’t have a faith belief (negative); doesn’t know if she can trust religion; doesn’t want to be let down – protective factor (positive); trying to find a belief (positive)</td>
<td></td>
</tr>
<tr>
<td>Large</td>
<td>Kelly</td>
<td>POSITIVE: God is back in her life again, after losing her faith</td>
<td></td>
</tr>
<tr>
<td>Large</td>
<td>Steph</td>
<td>POSITIVE and NEGATIVE: initially, saw the spiritual struggles as negative; now she sees them as positive because she’s moving forward to resolve them</td>
<td></td>
</tr>
</tbody>
</table>
Table 9: Impact of parent’s illness on participants’ emotional and physical well-being*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Summary of Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Small</strong></td>
<td></td>
</tr>
<tr>
<td>Billy</td>
<td>Emotionally: can understand extreme emotions</td>
</tr>
<tr>
<td>Rachel Kevin</td>
<td>Emotionally: felt anger/frustration, can understand extreme emotions, can appreciate positive emotions</td>
</tr>
<tr>
<td>Jackson</td>
<td>Emotionally: experienced psyc sx’s</td>
</tr>
</tbody>
</table>
| Denali      | Emotionally: experienced psych sx’s, felt unloved, anger/frustration, drained/stressed/worried  
Physical: doesn’t take care of self |
| **Large**   |                   |
| Lindsey     | Emotionally: experienced psych sx’s, hospitalized, emot rollercoaster, able to identify emotions  
Physical: self harm |
| Kelly       | Emotionally: experienced psyc sx’s  
Physical: sick more often after dad’s death, weak |
| Steph       | Emotionally: drained/stressed/worried  
Physical: weak, doesn’t take care of self |

*Positive impacts highlighted in bold
<table>
<thead>
<tr>
<th>Participant</th>
<th>Views on marriage/family and relationships with others</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Small</strong></td>
<td></td>
</tr>
<tr>
<td>Billy</td>
<td>None</td>
</tr>
</tbody>
</table>
| Rachel      | Marriage and Family: **No impact**
Relationships: **Understanding (ppl w/m.i., ppl in general)**, can’t open up (emotionally) to others, strives to make others happy
Relationships-family: family tension – who should take care of ill parent?
Relationships-friends: more outgoing, emotionally closed |
| Kevin       | Marriage/family: **equipped to handle m.i. in future spouse**
Relationships: **Understanding (ppl w/m.i., ppl in general)**, can’t open up (emotionally) to others |
| Jackson     | Marriage/family: **doesn’t understand why m.i. should have a neg impact**
Relationships: **Understanding (ppl w/m.i., ppl in general)**, learned how to deal with m.i., understanding |
| Denali      | Marriage/family: **wants marriage/family**
Relationships: **Understanding (ppl w/m.i., ppl in general)**, **more compassion**, can’t open up (emotionally) to others
Relationships-friends: friends turn to her for support |
| **Large**   |                                                      |
| Lindsey     | Relationships: **considerate of others, cognizant-how bx’s affect others**, can’t open up (emotionally) to others,
Relationships-family: decreased relationship w/ill parent
Relationships-friends: **improved, strengthened, close, supportive friends** |
| Julie       | Marriage/family: doesn’t want a relationship like parents – wants marriage and family, wants passionate marriage
Relationships: hard time trusting others, can’t open up (emotionally) to others
Relationships-family: decreased relationship w/ill parent, bothersome that can’t turn to non-ill parent for support
Relationships-friends: **improved, strengthened, close, supportive friends** |
| Kelly       | Marriage/family: believes it’s not possible to have “normal” relationship with someone, doesn’t believe in love, marriage not a big deal
Relationships: **understanding (ppl w/m.i., ppl in general)**, hard time trusting others, can’t open up (emotionally) to others
Relationships-family: decreased relationship w/ill parent |
| Steph       | Marriage/family: wait a while to marry – get life together first, doesn’t want to be a caretaker to spouse
Relationships: hard time trusting others, can’t open up (emotionally) to others
Relationships-family: can’t turn to family, extended family turned back on her family, must be parent’s strength
Relationships-friends: friends turn to her for support, older friends (searching for a role model), hard time putting self “out there” |

*Positive impacts highlighted in bold*
Table 11: Impact of parent’s mental illness on views of self, strengths, and limitations*

<table>
<thead>
<tr>
<th>Participant</th>
<th>View of self, strengths, limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Small</strong></td>
<td></td>
</tr>
</tbody>
</table>
| Billy       | Sees self in world: **strong, independent, positive future**  
Strengths: **stronger, independent, able to handle a lot, understanding**  
Limitations: **None** |
| Rachel      | Sees self in world: **strong, independent, more mature, positive future**, wishes didn’t have to do everything for self  
Strengths: **stronger, smart**  
Limitations: emotionally closed |
| Kevin       | Sees self in world: **strong, independent, positive future**  
Strengths: **stronger, independent, understanding, better person**  
Limitations: emotionally closed |
| Jackson     | Sees self in world: **no impact**  
Limitations: **None** |
| Denali      | Sees self in world: **strong, independent, more humble**  
Strengths: **stronger, independent, understanding, better person, compassionate, more humble, good communicator**  
Limitations: emotionally closed |
| **Large**   |                                      |
| Lindsey     | Sees self in world: **strong, independent, considerate, small role in world**  
Strengths: **stronger, independent, cognizant of how her bx’s affect others, small role in world, considerate, able to ID an issue/work on it**  
Limitations: poor communication skills, emotionally closed |
| Julie       | Sees self in world: **strong, positive future**  
Strengths: **stronger**  
Limitations: emotionally closed |
| Kelly       | Sees self in world: **strong, positive future, big role in world**  
Strengths: **stronger**  
Limitations: emotionally closed |
| Steph       | Sees self in world: **strong, independent, positive future**, questions her purpose in life, scared to put self “out there”  
Strengths: **stronger, independent, able to handle a lot**  
Limitations: emotionally closed |

*Positive impacts highlighted in bold*
Table 12: Participants’ reports of needing/wanting to resolve their spiritual struggle

<table>
<thead>
<tr>
<th>Loss Category</th>
<th>Exemplar Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small</td>
<td><em>Rachel</em> – “I wasn’t really sure what to believe, and I was angry at God, and I was angry at my family (laughs). I was angry at my mom. I was angry at anyone who was happy (laughs). But...I just got over it. You hit a point where you just don’t want to...reject it [religion/spirituality] anymore, you don’t want to pity yourself anymore, you just wanna, like, get out of that hole.”</td>
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<tr>
<td>Denali – “It [mom’s mental illness] definitely made me crave that spiritual community even more just because...I needed that comforting. I needed that support, and that belief that something else is taking care of everybody other than just us.”</td>
<td></td>
</tr>
<tr>
<td>Large</td>
<td><em>Steph</em> – “I’m still resolving those issues [religious/spiritual] now as we’re speaking. How I’ll feel a year from now, or two years from now...I think it’ll be a lot more positive, and I’ll have a better outlook on everything...Yeah, I won’t ever give up on it...it is something very important in my life. I do know when I pushed it out of my life totally, I didn’t like myself and I didn’t like that feeling. So, I don’t want to go back to that, so, I can only look forward now. I move forward and maybe ten years, maybe a little more, I’ll just keep doing that.”</td>
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<tr>
<td><em>Kelly</em> – “I just finally wanted, I just needed something to believe in.”</td>
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<tr>
<td><em>Kelly</em> – “I feel a lot more religiously based, like I found my center...I see myself [in the future] going to church every once in awhile and having that faith completely restored.”</td>
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<tr>
<td><em>Lindsey</em> – “Hopefully, in that period of time, I’ll get some answers, or at least be able to turn to her [mom] for answers, and, then, get some of this [spiritual struggles] resolved...hopefully within ten years I’ll be able to, um, either have them [answers] through my own spirituality or be able to go to her about them and talk to her.”</td>
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<tr>
<td><em>Lindsey</em> – “I’ve gotten so far from where I was [religiously/spiritually], that I don’t have the connectional base here. But at the same time, I feel like if I can, it’ll be proving something to God to show Him that I can find my way back – that I can, you know, through everything that’s going on, I can still find my way back, and still be able to connect with Him.”</td>
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<tr>
<td><em>Julie</em> – “I feel like having a religion...in your life is a good thing. I feel like it’s almost a reason to live, you know, something to look forward to...So it’s [religion]...essentially something you’re working towards in your life...I don’t know why, I can’t really explain it, but I sometimes picture myself raising my kids Christian...I don’t know where I see myself religiously ten years from now. But, I don’t see myself not religious.”</td>
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</tbody>
</table>