Grief in Parents of Adults Experiencing Early Psychosis

A Dissertation

SUBMITTED TO THE FACULTY OF THE UNIVERSITY OF MINNESOTA

BY

Anne Williams-Wengerd

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

Dr. Catherine Solheim

May, 2022

Acknowledgements

I acknowledge and give gratitude to my advisor, Dr. Catherine Solheim, without whom this project would have been impossible. You have pushed and challenged me while simultaneously providing consistent support. Thank you.

I acknowledge my entire committee for their service. Thank you to Dr. Lindsey Weiler who provided countless hours of mentoring and support during my graduate education. Thank you also to Dr. Piper Meyer-Kalos, who has reminded me many times of the real-world impact of my research. Thank you also to Dr. Tai Mendenhall, for your many hours of service and encouragement during this process.

I acknowledge my numerous teachers and mentors throughout my lifetime who have all contributed to my education: Mrs. Alvern Bjerke, Dr. Eric L. Johnson, Dr. Jason Li, Dr. James Koch, Julie Grothe, Martin Marty, Dr. Lindsey Weiler, Dr. Catherine Solheim, Judith Condon, Dr. Andrea Olson, Dr. Jamie Peterson, Dr. Kai Gunty, and Dr. Gabrielle Filip-Crawford.

I acknowledge all of the brave and courageous parents who participated in this research. Your authenticity and willingness to share so freely about your life experiences have been a gift and an inspiration. Thank you.

Last but not least, I acknowledge all of the strong women in my family who proceeded me and exhibited tremendous resilience throughout their time on this earth: Ida Tangen, Ina Tangen, and Virgie Sebekow.

Dedication

This dissertation is dedicated to my dearest ones: my amazingly supportive spouse and partner in this life, Isaac Wengerd; my beautiful and insightful children, Henry and Gus Wengerd; and my most ardent champion and the strongest woman I know: my mom, Cheri Stallman.

Thank you all for loving me so dearly despite my numerous flaws. I am so grateful to call you my family. You have provided me with a solid and true foundation during this challenging process, and you continue to teach me everyday about how to love myself and others better.

“To live in this world
you must be able
to do three things:
to love what is mortal;
to hold it
against your bones knowing
your own life depends on it;
and, when the time comes to let it go,
to let it go.”

“In Blackwater Woods” by Mary Oliver

Abstract

Research has shown that early psychosis, the first five years following the initial onset, is a critical period when treatment is most needed for patients. Because the onset of early psychosis usually occurs in late adolescence/early adulthood, parents are often the most likely family members to be involved in their child's treatment. Existing research on parents of adults experiencing schizophrenia has shown that parents experience a loss of future hopes for their child as well as a loss of their previous relationship with their child.

Ambiguous loss theory provides a relational lens through which to understand grief in unclear and complex circumstances. Given the salient and influential parent-child relationship, the use of an ambiguous loss lens to understand grief in parents of individuals with early psychosis could lead to a more systemic understanding of the relational nature of the grief that parents experience. It could thereby more effectively inform interventions for parents.

In this dissertation, I conducted both a quantitative and qualitative study to explore the application of ambiguous loss theory to the experiences of parents of adults with early psychosis. The results of the survey showed that parental grief was strongly associated with the experience of boundary ambiguity, whereby parents struggled to understand their child's role and their own role in their family. From conducting in-depth interviews, I found that parents experienced considerable uncertainty about their relationship with their child, and how to respond to the changes in their child, given the onset of psychosis. The results from both studies show that ambiguous loss theory provides an important lens through which to understand the complex and unpredictable experiences of parents of adults with early psychosis.

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List of Abbreviations

SMI: Serious Mental Illness

CSC: Coordinated Specialty Care

NAMI: National Alliance on Mental Illness

PEPPNET: Prodromal and Early Psychosis Provider Network

PCASS: Parent Child Affectional Solidarity Scale

MIV-TIG: Mental Illness Version of the Texas Inventory of Grief

CESD:10: Center for Epidemiologic Studies Depression Scale 10

VIF: Variance Inflation Factor

Chapter 1

Introduction

Psychosis occurs in approximately 3% of the population, and the first five years following the onset of psychosis is a critical period when individuals and families are most in need of treatment and intervention (Lieberman & Fenton, 2000; Malla et al., 2005). Early psychosis most often occurs during a time of significant developmental change when young people are transitioning from late adolescence into young adulthood, gaining greater independence and autonomy from their families, and navigating changing family relationship dynamics (Livesey et al., 2016; Norman et al., 2004; Onwumere et al., 2011). Although their typical developmental trajectory would be toward greater self-sufficiency, young adults experiencing early psychosis are often in need of increased support from their families, which is most frequently provided by parents (McCann et al., 2011; Mulligan et al., 2013).

Having an adult child facing psychosis can be stressful, disorienting, and emotionally painful (Addington et al., 2005). Moreover, research has shown that parents often experience grief in reaction to the onset of their child's mental illness (Marsh & Johnson, 1997; Miller et al., 1990; Osborne & Coyle, 2002; Richardson et al., 2011). The grief parents experience is often filled with shock related to an abrupt onset of psychosis (Darmi et al., 2017; Wiens & Daniluk, 2009) and uncertainty related to its future course (Richardson et al., 2013). Parents must frequently adjust their expectations of their child's present and future ability(ies) to function independently, and thereby experience significant shifts in their relationship with their child (Stein et al., 2013; Williams-Wengerd & Solheim, 2021).

Current research on families' response to early psychosis has focused on caregivers' generalized experiences. Most studies do not consider how different types of family relationships might affect caregiving. As a result, we know little about how

parents, who have unique and enduring relationships with their children, are impacted by their adult child's early psychosis journey. Family theory offers an important lens through which to understand parents' experiences. In particular, understanding the tenets of ambiguous loss theory helps families normalize the inherent difficulty of understanding losses which lack clarity, and highlights how factors such as boundary ambiguity and tolerance of uncertainty can impact an individual's ability to process grief (Boss,1999, 2006, 2016; Boss et al., 1990).

Fortunately, efforts over the last 20 years have been made to include families in early psychosis intervention. Community Specialty Care (CSC) programs such as NAVIGATE (Mueser et al., 2015) open opportunities to explore the impacts that early psychosis has on families. Although the shift to include families in early psychosis treatment is promising, there is still a paucity of research exploring grief in *parents* of adults with early psychosis from a family perspective.

The goal of this dissertation research is to explore grief in parents of adults experiencing early psychosis and to investigate the application of ambiguous loss theory to their experiences. Parents' experiences are significant. Research has demonstrated that parents' grief is associated with decreases in parental well-being (Godress et al., 2005) and that parents' emotional responses can impact their child's recovery trajectory (Hooley et al., 2007). Given the lack of research on parental grief associated with early psychosis and its effect on both parents and their adult child, it is essential that researchers investigate the specific experiences of grief in parents. Results from this research can be used to gain an understanding of parents' complex experiences. Moreover, results may also contribute to the development of interventions that integrate parents' unique role in early psychosis treatment and long-term care so that individuals experiencing early psychosis are better supported in their recovery.

Background

Psychosis results in behavior that is often dramatically inconsistent with how a person behaved prior to onset. This behavior can be loosely defined as a disconnection from reality (NIMH, n.d.). Psychosis typically occurs during a stage of life in which individuals are experiencing numerous changes in their lives, including increased responsibilities and/or expanded independence from parents. Moreover, intervention efforts have focused predominantly on the early stages of psychosis because research has shown that this a pivotal period of time during which treatment is most likely to improve outcomes for individuals experiencing psychosis (Malla et al., 2005; Mueser et al., 2015).

In this dissertation, I use a definition of early psychosis recommended by Breitborde et al. (2009), who asserted that time from the onset of symptoms is the most coherent way to describe early psychosis. Thus, early psychosis will be defined as the experience of non-affective psychosis (a schizophrenia spectrum disorder diagnosis) for less than five years. The two studies included in this dissertation will focus on parents of adults experiencing non-affective psychosis for less than five years, subsequently referred to as early psychosis.

Past research on parents of adults experiencing schizophrenia who are not in the early stages of their illness has shown that parents often retrospectively report a period of considerable distress (sadness, anger, helplessness, uncertainty, guilt) following the onset of symptoms in their children (Wiens & Daniluk, 2009; 2017). Other studies have found that parents have endorsed feelings of loss of their child as they knew them prior to onset and that grief is a common response to the stress of their child's illness (Godress et al., 2005; Stein et al., 2013). This grief also appears to be complicated by feelings of guilt related to misattributing symptoms to normal development, and

uncertainty about the diagnosis and prognosis of their child's mental health condition (Johannson et al., 2012; McAuliffe et al., 2014).

Recognizing the need for or becoming involved in treatment is complicated for parents, and their lack of involvement can negatively impact treatment for their child (Iyer et al., 2020). Young adults specifically are often launching from their parents' care into greater independence and exercising their increased rights regarding healthcare privacy. In the United States, if a child is over 18 years old, parents are not allowed to engage in communication with mental health providers unless their child specifically provides consent due to confidentiality and health information laws. Due to mental health stigma (Cavelti et al., 2014), individuals experiencing psychosis may be reluctant to tell their parents about their experiences with psychosis and even more reluctant to allow communication between their parents and their providers. Thus, parents initially may not even be aware of their child's illness and/or treatment. Unfortunately, data show that delayed treatment for psychosis can be detrimental to recovery (Perkins et al., 2005) and even have impacts on their child's mortality (Reininghaus et al., 2015).

The mental health field has responded to the need for early intervention by developing coordinated specialty care (CSC) programs that aim to not only serve individuals experiencing early psychosis, but also to include family members in treatment. Many of these programs provide family education programming whereby the treatment team can develop a relationship with the family, provide education about psychosis, and "enlist the support" of loved one's engagement in treatment (Mueser et al., 2015, p. 682). Because of increased clinical and scholarly attention on early intervention for psychosis (Mueser et al., 2015), there is a growing body of research that prioritizes the important and interconnected experience of family members of individuals with early psychosis (Domínguez-Martínez et al., 2017; Lal et al., 2016). However, research on family members' experiences has largely focused on the experience of

caregiving in general (Dawson et al., 2012; McCann et al., 2011; Mulligan et al., 2013), with little specific attention to the unique experiences of parents.

Despite the more general focus on “caregivers” of individuals with early psychosis, parents continue to make up a large portion of participants in these studies. For example, caregiver samples in Mulligan et al. (2013) and McCann et al. (2011) were 86.7% and 85% parents respectively. In both of these studies, participants endorsed experiences of grief as well as a considerable sense of responsibility for their loved one’s illness. Additionally, researchers have found that caregivers (many of whom were parents) experienced intense grief, guilt, and worry following the onset of psychosis, and that they largely ignored their own needs in order to prioritize the care of their loved one (Cairns et al., 2015; Dilinger & Kersun, 2018).

Although parents are often the most likely people to provide caregiving to individuals experiencing psychosis (Cairns et al., 2015; Luckstead et al., 2016; Mulligan et al., 2013), we also know from family theory that parents have a critical role in their adult child’s life whether or not they provide direct caregiving. Because the onset of psychosis tends to occur at a time of greater expectation of independence and autonomy, parents experience uncertainty and lack a clear understanding of their role in their adult child’s life (Cairns et al., 2015). Thus, parents struggle with how to support their young adult child experiencing early psychosis while simultaneously recognizing their new legal independence and right to confidentiality.

Moreover, because parents are often de facto caregivers to their children experiencing early psychosis, they typically have had an intimate and long-term relationship with their child. Therefore, the grief these parents experience is unique, deeply personal, and deserving of greater attention. However, despite the complexity of parents’ roles in responding to early psychosis in their adult children, there is scant research investigating grief specifically in parents of adults with early psychosis.

Past literature on grief has largely focused on individual experiences of grief and loss, often in response to the death of a loved one (Freud, 1957; Kubler-Ross & Kessler 2005). However, research done on families experiencing mental illness reveals that mental illness can trigger a profound sense of loss, not only for the individual experiencing the illness, but for their entire family (Marsh & Johnson, 1997). In addition, mental illness is often accompanied by negative stigma and a lack of social support (Gonzalez-Torres et al., 2007; Jones, 2004). Grief research has historically distinguished "pathological from normal grief" (Richardson et al., 2011, p. 29); however, emerging theories of grief, such as ambiguous loss, prioritize the importance of accepting a lack of clarity regarding loss and recognizing the relational and normative nature of grief (Boss, 1999, 2006, 2016).

The presence of parental grief has significant implications for the parent's as well as their child's wellbeing. Although research about grief in parents of adults experiencing psychosis is still exploratory, theory and preliminary investigations show that parents' relationships with their children impact the child's recovery (Hinojosa-Marqués et al., 2019; Iyer et al., 2020) and that grief has a negative impact on the parents' well-being (Godress et al., 2005). Further, there is evidence to support a positive association between parental relationship quality and parental well-being (Greenberg et al., 2004). We also know that parents' intense emotional responses to their child experiencing psychosis are associated with a relapse of psychotic-related symptoms (i.e., expressed emotions; Ng et al., 2019), and there is some evidence that parents' attachment to their child mediates the relationship between parents' grief and their response to their child through expressed emotions (Hinojosa-Marqués et al., 2019).Thus, research, grounded in family theory is still needed to more fully understand the predictors of parental grief.

Theoretical Foundations

This research is supported by four family-related theories. Attachment theory, life course theory, family stress and resilience theory, and ambiguous loss theory all make important contributions to understanding parents' experiences with their adult children experiencing early psychosis.

Attachment Theory

The centrality of the relationship between a parent and their child is strongly supported by attachment theory (Bowlby, 1980; Miklulincer & Florian, 1998). This theory is grounded in the assumption that human beings are intrinsically motivated to develop connections with their caregivers (most often parents), and that these relationships provide individuals with a guide or a model for how to develop future relationships. These are also known as "internal working models" (Bowlby, 1980; George & Solomon, 2016). Although most research has focused on children's internal working models, it is important to note that parents also have internal working models through which they understand their relationships with others including their own children. Parents models were developed by their own experiences of receiving care from their parents and are modified as they care for their offspring. Moreover, parents develop a caregiving system based on who they know their child to be. As a result, they respond to and care for their adult child based on their previous experiences and understanding of what their child needs. However, it would seem likely that psychosis-induced changes in their child's personality and behaviors would eventually alter the mental representation parents have of their adult child, causing parents to feel stress, anxiety, and grief. The changes also prompt parents to shift their understanding of their relationship with and how they relate to their child (Godress et al., 2005; Stein et al., 2013). Together with the uncertainty of the mental illness itself, these less tangible and more ambiguous relationship changes could contribute to their sense of loss and grief following the onset of psychosis.

Life Course Theory

Life course theory offers a dynamic lens through which to consider how the onset of psychosis in adolescence/early adulthood impacts not only the individual with the illness, but also the parents (Aldous, 1990; Cook et al., 1997; George, 2007). Life course theory assumes that timing, context, interdependence, and culture all affect the family (Allen & Henderson, 2017; George, 2007), so the different developmental stages of parent and the child with early psychosis and their respective experiences of the illness will be mutually influential. For example, the young adult is in a stage of increased independence and launching from their family, and the parents also anticipate the increased independence of their child. The experience of early psychosis may result in frustration by the young adult who cannot exercise their increased independence, and parents may simultaneously experience a loss of their own freedom due to expanded caregiving responsibilities for their child.

Linked lives, the idea that lives of family members (particularly parents and children) are interwoven and interconnected, is a key construct in life course theory. Research shows that the mental well-being of parents following the onset of a child's serious mental illness (SMI) decreases (Godress et al., 2005). Reciprocally, when a mental illness becomes chronic, longevity is decreased in the individual living with it (WHO, n.d.). Moreover, a parent's response to their child's illness will impact their child, with evidence showing better outcomes for individuals living with SMI when their family is involved in their care (Reininghaus et al., 2015).

Family Stress and Resilience Theory

Family stress and resilience theory offers a lens to examine how families respond to a stressor such as the onset of psychosis. The double ABCX model (McCubbin & Patterson, 1983) outlines factors that contribute to the understanding of how psychosis impacts parents. For example, psychosis is an unpredictable stressor that changes and

builds over time. The concept of “stressor pile-up” applied to psychosis would assert that the build-up of stressful events such as repeated hospitalizations or difficulty accessing treatment can precipitate a crisis (Onwumere et al., 2017). Perception of a stressor is essential to understand its impact. For early psychosis, parents struggle to understand what their child is experiencing and have difficulty getting clarity about diagnosis and prognosis from treatment providers (Cairns et al., 2015). They experience changes in their perceptions of their and their child’s roles in the family as the illness plays out.

Ambiguous Loss Theory

Ambiguous loss theory provides a relationally-informed and novel lens through which to understand early psychosis and the associated losses that are filled with uncertainty and lack clarity in many facets of the illness and the parent-child caregiving relationship (Boss, 1999; 2006). There is ambiguity surrounding diagnosis. Parents may not initially identify that their child is experiencing mental health symptoms (i.e. the prodromal period). Although not all individuals experience a prodromal period, it is typically a period of time before the acute onset of psychosis when individuals experience social withdrawal, increased depression, and/or anxiety (Yung & McGorry, 1996). Parents may often attribute these symptoms to typical adolescence. Further, if parents seek treatment from general medical providers, these professionals may not identify the experience as psychosis and/or their child may not articulate their psychotic symptoms to a provider. Thus, the diagnosis can be unclear. Adding to the ambiguity is that the prognosis is often imprecise; not all individuals experiencing psychosis follow a chronic trajectory. The inability to know what the future will hold is particularly stressful for the family.

Because of the developmental stage of the onset of early psychosis, parents have known and cared for their child for many years and often experience a sudden change in how their adult child presents. Past researchers have stated that parents

experience a loss of who they knew their child to be prior to the illness (Richardson et al., 2011). The ambiguities surrounding their child's circumstances now and into the future contribute to parents simultaneously experiencing their child as physically present and psychologically absent.

In this situation, boundaries may become ambiguous or blurred as family members wonder what, if any, role they will play as their illness unfolds. Without support to help parents recognize and name this as grief and loss, parents may be reluctant to talk about their child and their own distress. According to ambiguous loss theory, the ability to tolerate uncertainty and accept the ambiguity of a loss can aid a parent from becoming "frozen" in their grief. More specifically, the inability to tolerate uncertainty and determine their child's role in the family may result in parents having difficulty processing their grief. Conversely, if a family member can tolerate uncertainty and accept the new and ambiguous role that their child may have in the family, they will be more likely to identify and process their grief.

Although the aforementioned theories are useful in framing research that examines the parent-child relationship when an adult experiences early psychosis, ambiguous loss theory provides a specific lens through which to understand the type of losses that seem to surround this phenomenon. These experiences include: losses that lack clarity and are on-going with no predictable end in sight, losses that involve relationship factors such as boundary ambiguity, and losses that require an ability to tolerate uncertainty, all of which can impact an individual's ability to process grief (Boss et al., 1990; Boss, 1999).

The recent shift to include families in the treatment of individuals with early psychosis opens opportunities for the creation of much-needed family-based interventions. While this shift is promising, there is still a significant gap in our understanding of how early psychosis uniquely impacts parents and their relationships

with their children, namely the nature of their grief and loss connected to their relationship with their adult child who has experienced early psychosis. The goal of this dissertation project is to explore grief in parents of adults with early psychosis and examine the application of ambiguous loss theory to this experience.

Study 1

In the first study, *Exploring predictors of grief in parents of adults with early psychosis: An ambiguous loss perspective*, I examined the impact of parental relationship quality and ambiguous loss variables on parental grief. Parents of adults with early psychosis (n=30) were recruited from numerous mental health support agencies to complete an online survey that assessed their relationship quality with their adult child (Parent Child Affectional Solidarity Scale; Silverstein & Bengtson, 1991), their experiences of grief (Mental Illness Version of the Texas Inventory of Grief; Miller et al., 1990), their experiences of boundary ambiguity (Boss et al., 1990) and their intolerance of uncertainty (Carleton et al., 2007). Utilizing hierarchical regression, I tested the impact of parental relationship quality on grief and the additional variance that ambiguous loss factors contributed to parental grief above and beyond that of parental relationship quality. In the first model, I tested the impact of parental relationship quality on parental grief. In the second model, I tested the combined impact of boundary ambiguity (Boss et al., 1990) and parental relationship quality on parental grief. In the third model, I tested the combined impact of both parental relationship quality and intolerance of uncertainty (Carleton et al., 2007) on parental grief. See Appendix A for all measures and items. Finally, to better understand the sample of parents in this study, I conducted a post hoc analysis to examine the association between parental grief and parental depression.

Study 2

In the second study, *The nature of grief in parents of adults experiencing early psychosis,* I explored the grief experiences of parents of adults with early psychosis. I

conducted 13 interviews of parents of adults experiencing early psychosis (See Appendix B for interview guide) and analyzed the interview data using a hermeneutic phenomenological framework. In Table 5, I show that the nature of parents' grief could be described by three overall themes occurring in three domains:

- parents' uncertainty about: (a) their child, (b) their relationship with their child, and (c) their own experiences including their role in their child's life
- overwhelming emotions about: (a) their child; (b) their relationship with their child and (c) their role in their child's life
- paradox of holding on and letting go of: (a) their child, (b) their relationship with their child, and (c) their role in their child's life

I then explored how these experiences aligned with constructs in ambiguous loss theory. My conclusion was that ambiguous loss theory, particularly parents' uncertainty, was consistent with how they described their experiences of grief. An additional theoretical connection that emerged from my phenomenological analysis offered a nuanced idea related to Boss's paradox of physical presence and psychological absence. I found that parents experienced their children as physically present and precariously psychologically present. Parents described their children experiencing psychosis as not fully psychologically absent. Rather there were times when their child as they previously knew them was present, and at other times when their child disappeared, and a very different, and sometimes violent individual appeared. The most difficult thing for parents was the uncertainty that preceded encounters with their adult child; they never knew "who" would "show up."

There are implications of this dissertation research for both researchers and clinicians. First, grief in parents of adults with early psychosis appears to be inextricably connected to their uncertainty about their child's role and their own role in their child's

life. Future researchers should explore the construct of boundary ambiguity in families experiencing mental illness and how it contributes to loss and grief.

Second, although parents varied in how they responded to psychosis in their children, they all described significant uncertainty. Many parents described an experience that required them to hold a paradox of maintaining a relationship with their child while letting go of aspects of images of their child, their relationship with their child, and their own role in their child's life. In navigating constant uncertainty, parents experienced overwhelming emotions, changes in their expectations, and changes in how they related to their child. These findings lay the foundation for future research on the development of interventions that can support not only parents of adults experiencing early psychosis, but also individuals living with psychosis.

Chapter 2

Predictors of Grief in Parents of Adults Experiencing Early Psychosis

Research on grief in parents of adults experiencing early psychosis is noticeably limited. Existing grief studies focus more broadly on a broad category of caregivers without distinguishing a specific family member's role and how that might affect their grief experience. The research appears to assume that family members, irrespective of their family role (e.g., parent, child, sibling, etc.), grieve similarly.

In this study, I examined the correlation between parent-adult child relationship quality and parents' grief following the onset of their child's early psychosis using data from a survey of 30 parents. Informed by the concepts of internal working models and caregiving systems from attachment theory, I also explored how concepts from ambiguous loss theory, including measures of boundary ambiguity and tolerance of uncertainty, predicted parents' grief.

Findings from this study showed that while parental relationship quality appeared to be negatively and significantly associated with parental grief, and that parents' boundary ambiguity – that is, their perception of uncertainty about their changing role with their adult child with early psychosis explained more of the variance in parental grief over and above parents' relationship quality with their child. Parents' overall intolerance of uncertainty did not predict parental grief. These findings have important implications for researchers who study the topic of parental grief and for clinicians who want to develop novel and supportive interventions for parents of adults experiencing early psychosis.

Background

The first five years following the onset of non-affective psychosis (early psychosis) represents a critical period when treatment and intervention are most needed for patients (Lieberman & Fenton, 2000). For this study, I used the definition of early

psychosis recommended by Breitborde et al. (2009), who asserted that time from the onset of symptoms is the most coherent criterion. Thus, early psychosis in this study was defined as the experience of non-affective psychosis (a schizophrenia spectrum disorder diagnosis) for less than five years.

Although there has been considerable research on parents of adults experiencing serious mental illness (SMI), there has not been this same focus on parents of adults with early psychosis (Richardson et al., 2011; Williams-Wengerd & Solheim, 2021). Complicating this research further is that individuals who experience early psychosis can later experience what would be classified as SMI (NIMH, n.d.). Thus, it is important to clarify the distinction of early psychosis in this study.

First, SMI can include, but is not limited to, individuals with schizophrenia spectrum disorders. The primary difference between SMI and early psychosis is the length of time since onset of the illness. Individuals with SMI have often been experiencing chronic and prolonged symptoms of their illness (i.e., longer than five years) including significant impairments in functioning. However, adults with early psychosis are typically in the early stages of specifically psychotic symptoms and may or may not experience serious functional impairments at a later time.

Research on access to treatment interventions for individuals experiencing psychosis soon after onset has expanded considerably in the last 20 years (Dixon et al., 2015; Mueser et al., 2015). Despite this expansion of research on early psychosis, the research on parents of adults with early psychosis has not followed suit. Rather, it has focused more generically on “caregivers” with a lack of distinction of the caregivers’ role (e.g., parent, sibling, friend, etc.) in relationship to the patient.

Although most of research on family response to early psychosis focuses broadly on caregivers (Cairns et al., 2015; Dilinger & Kersun, 2018; Onwumere et al., 2017), existing research on grief in parents of adults with SMI shows that parents’ experience

the most intense grief in the early stages of their child's illness (Godress et al., 2005). Therefore, it is essential that researchers examine the distinct experience of *parents* of adults with early psychosis. This is important for multiple reasons. First, parents are often the most likely family member to provide caregiving to their child experiencing early psychosis (Cairns et al., 2015: McCann et al., 2011). Second, parental relationships with their adult children are distinct from sibling relationships or romantic partner relationships. Whereas there is often a relatively equal amount of shared power in sibling or romantic partner relationships, parents typically are charged with both legal and relational responsibilities to care for their children prior to age 18 years. Lastly and most importantly, parents have typically nurtured and cared for their child over many years, resulting in a significant emotional investment in the relationship with their child. By the time a child becomes an adult, parents have developed beliefs about who their child is as well as hopes and expectations regarding their child's future, and the onset of psychosis represents a stark change in their child (Addington et al., 2005). Because changes in the adult child caused by early psychosis often result in the emergence of a markedly different adult child than parents knew prior to the onset of the psychosis (Luckstead et al., 2016), parents may experience uncertainty and grief (Richardson et al., 2011).

Godress (2005) cited Davis and Schultz (1998) in defining grief as a as a reaction to loss which includes cognitions, behaviors and emotions (Godress et al., 2005, p. 88). Although past literature has focused on the individual experience of grief, often in response to the death of a loved one (Freud, 1957; Kubler-Ross & Kessler, 2005), research with families experiencing mental illness has revealed that mental illness triggers a profound sense of loss and grief, not only for the individual experiencing the illness, but for their entire family (Marsh & Johnson, 1997). The loss and grief experienced by family members are complicated by the negative stigma and

lack of social support (Gonzalez-Torres et al., 2007; Jones, 2004) that often accompany mental illness. Research has shown that families of individuals experiencing SMI have concerns about being judged by others regarding stigma (Huang et al., 2016), and that this stigma may only serve to compound parents' grief (Jones, 2004). Rather than experiencing support, parents may feel that there is something wrong with them or their family. In addition, research has found that that grief in parents of adults with SMI is associated with decreased health and well-being parents (Godress et al., 2005) and that family members of adults with SMI experiencing grief are at greater risk of depression (Chen & Lukens, 2011).

Research on grief in parents of adult children with SMI (Richardson et al., 2011; Williams-Wengerd & Solheim, 2021) has suggested that parents experience considerable grief, and that a parent's relationship with their child is impacted by the illness (Stein et al., 2013). Parents of individuals with SMI struggle to maintain a connection to their child while they are also managing their loss of expectations for their child (Johansson et al., 2012; White & Unruh, 2013) and a loss of social support (Landon et al., 2016; Stein et al., 2013).

Contrasted with research on grief in parents of adults with SMI, the research on grief in response to early psychosis has been limited to the experience of caregiving in general, even though parents continue to make up a large portion of participants in these studies. For example, Mulligan et al. (2013) found that parents comprised 86.7% of their study's sample of caregivers, and that these caregivers experienced considerable grief. Similarly, Dilinger and Kersun (2018) found in their systematic review of literature on caregivers of individuals experiencing early psychosis, that caregivers (largely parents) experienced considerable grief and guilt following the onset of psychosis. Similarly, McCann et al. (2011) found that caregivers (17 of 20 were parents), felt a considerable sense of responsibility for their loved one's illness.

Although current research on caregivers is drawn from samples of mostly parents, researchers have not acknowledged the distinct role of parents and how parents may experience grief differently from loved ones in other family roles. From theory (e.g., attachment theory), it is widely accepted that parents have a unique and important caregiving role in their relationship with their child throughout their life. However, what is not clear from current research is how parents of adults with early psychosis experience grief. Because parents have a distinct and paramount relationship with their child, research is needed to better understand parents' grief and their relationship with their child experiencing early psychosis.

Theoretical Foundation

Attachment Theory

Attachment theory provides a well-established conceptual foundation for understanding the importance of parent-child relationships. Even though attachment theory was originally directed towards understanding parent and infant/child attachment, Bowlby and his predecessors asserted that attachment theory could be applied throughout human development (Bowlby, 1980; Miklulincer & Florian, 1998). Moreover, there is evidence to support that attachment between a parent and child is impacted not only by the present relationship between the parent and child but also by the parents' experience of attachment in their own relationship with their parent (Cohn et al., 1992).

One assumption of attachment theory is that all individuals are predisposed to seek meaningful relationships with their caregivers (Bowlby, 1980; Miklulincer & Florian, 1998). Moreover, it is largely these relationships (typically with parents) that provide a framework or an internal working model for how individuals engage in later relationships (Bowlby, 1980). That is, individuals establish ideas of how relationships work early in life through their interactions with caregivers or parents. These early experiences of

attachment are woven into an internal working model that becomes a template for how individuals expect relationships to work throughout our life.

As individuals become parents, they draw on the internal working model they created, based on the interactions with their own parents, to parent their offspring. In other words, parents have internal working models for relationships and these models influence their sensitivity in the caregiving of their children as well as their ability to be a safe haven for their child in times of stress (Magai et al., 2016; Shaver et al., 2016). Internal working models provide parents with a map by which they organize their own caregiving system, guided by mental representations that are “specific to the child” (George and Solomon, 2016, p. 840). These mental representations are shaped by an individual’s beliefs, attitudes, and expectations (Gillath et al., 2016).

This experience of caregiving for a child with psychosis stands in contrast to a parent’s previous experience of caregiving, and their mental representation of who that child is. The changes parents encounter when their child experiences early psychosis occur for multiple reasons. First, the onset of psychosis in young adulthood represents an alteration in how parents anticipated their child’s developmental trajectory. Rather than providing decreased caregiving, parents of adult children with psychosis are often required to expand their caregiving role. Second, the onset of psychosis in young adulthood is often experienced as a loss of their child. Because psychosis often involves a drastic change in behavior and how an individual acts and relates to others, it is also likely to cause a parent considerable emotional distress and grief (Hinojosa-Marqués et al., 2019; McCann et al., 2011). Thus, parents’ understanding of who their child is (their mental representation) and the parents’ internal working model of how they provide care to their child, requires modification. Psychosis alters how parents have previously expected their child to respond to them and their environment. Adult children experiencing psychosis may not be able to care for themselves (may not be able to work

or engage in school) and/or may need additional support (e.g., with housing, accessing mental health treatment). Children may even see their parents as a threat, rather than a comfort. This abrupt change in the relationship with their child is oftentimes distressing. Research has demonstrated that parents can have intense emotional responses to their child who is experiencing psychosis (e.g., expressed emotions; Koutra et al., 2014).

Studies on the impact of psychosis on the family have primarily focused on family pathology, namely the ways that family members negatively impact the ill family member's psychosis (e.g., expressed emotion research; Koutra et al., 2014; Ng et al., 2019). For example, research has pointed to the link between a family member's expressed emotions (criticism, hostility, or emotional over-involvement) and the increase or relapses of psychotic symptoms in the family member experiencing psychosis (Hooley, 2007; Koutra et al., 2014). Conversely, there is research that supports the idea that family interventions for individuals experiencing early psychosis show improved treatment outcomes for the individual experiencing early psychosis (Onwumere et al., 2018) and that family members can play important roles in treatment access (Luckstead et al., 2016). Thus, family members can positively affect illness trajectories and treatment outcomes.

Ambiguous Loss Theory

Although past grief research has often distinguished "pathological from normal grief" (Richardson et al., 2011, p. 29), emerging theories of grief, such as ambiguous loss theory, prioritize the importance of accepting a lack of clarity regarding loss and recognizing the relational and normative nature of grief (Boss, 1999). Ambiguous loss theory in particular provides a relationally informed and innovative lens through which to understand a loss that is filled with uncertainty and lacks clarity (Boss, 1999, 2006, 2016). The ambiguity parents experience following the onset of early psychosis in an adult child is at least two-fold. First, there is ambiguity surrounding the recognition of

psychosis itself. Parents may not initially recognize that their child is experiencing mental health symptoms (i.e., the prodromal period). Although not all individuals experience a prodromal period, it is typically a period of time before the acute onset of psychosis when individuals experience social withdrawal, increased depression, and/or anxiety (Yung & McGorry, 1996). Parents may often attribute these symptoms to typical adolescence. Further, if parents do seek treatment from general medical providers, these professionals may not identify the experience as psychosis and/or their child may not articulate their psychotic symptoms to a provider. Thus, the lack of a clear diagnosis contributes to an experience of situational uncertainty (Carroll et al., 2007).

Second, the prognosis of psychosis is often imprecise; not all individuals experiencing psychosis will follow a chronic trajectory. The ambiguity surrounding an individual's future outcomes and prognosis of psychosis (van der Ven et al., 2020) make it difficult for parents to know what will happen with their child as they move forward in life and how their own role and relationship with their child may change over time. This unknown future can be particularly stressful for the family. Moreover, having a child with early psychosis who is present in different ways from how parents and other family members have known them to be in the past, can exacerbate the complexity of the situation.

Because of the complex ambiguity and uncertainty surrounding the changes in their child experiencing early psychosis and changes in their own roles and relationships with that child, parents need support to recognize and name their experience as grief. Without this language, parents may be reluctant to talk about their child and their own distress. According to ambiguous loss theory (Boss, 1999, 2006, 2016), the ability to tolerate uncertainty and accept the ambiguity of a loss can prevent a parent from becoming "frozen" in their grief. More specifically, the inability to tolerate uncertainty and determine their child's role in the family may result in parents becoming overwhelmed by

the stress of the situation which could lead to depression and anxiety (Boss, 2006). Conversely, if a family member can tolerate uncertainty and accept their child's new and ambiguous role in the family, they will be more likely to identify and process their grief and adapt to the changes in their family.

Parents' history of emotional investment in their child, through nurturing and caregiving, combined with the situational uncertainty, only serves to further complicate parents' grief as well as their ability to navigate their relationship with their child following the onset of psychosis. Studying parental grief from a relational perspective is important for parents and those experiencing psychosis. The current research holds promise to expand researchers' understandings of grief in parents of adults experiencing psychosis and can lead to the development of interventions specifically tailored to those factors which are more predictive of parental grief.

Purpose

Previous research on early psychosis lacks a specific focus on parent experiences and the nature of the relationship between the parent and the child with early psychosis. Therefore, the purpose of this exploratory study was two-fold: a) to explore the predictors of parental grief and b) to examine how parents' anxiety (intolerance of uncertainty) and boundary ambiguity may expand what is known about grief in parents of adults experiencing early psychosis. Because past research has shown a strong association between grief and depression in parents of individuals with SMI, I also explored post-hoc the relationship between parental grief and parental depression.

H1: Parental relationship quality will be inversely associated with parental grief meaning that as parental relationship quality increases parental grief will decrease.

H2: Boundary ambiguity and intolerance of uncertainty will each explain additional variance in parental grief over and above parental relationship quality.

Method

Sample

To explore the predictors of grief in parents of adults with first-episode psychosis, participants were recruited from multiple mental health support programs including a listserv developed from a clinic-based first-episode psychosis program. Participants were also recruited from other programs including the National Alliance on Mental Illness (NAMI) Minnesota, NAMI Wisconsin, NAMI Iowa, NAMI New Hampshire, NAMI Washington, and PEPPNET (Prodromal and Early Psychosis Program Network). Snowball sampling was also used to increase sample size; participants who had already responded to the survey and provided their email address were asked to share study information with individuals from their networks who they thought would meet study criteria.

The final sample consisted of 30 individual parents (ages 46-70; 28 women, 2 men) from across the United States who identified as parents of adults (over age 18 years) experiencing psychosis that had started within the last five years. Twenty-seven parent participants indicated they were married and living with their spouse. Twelve participants reported living with their child experiencing psychosis (note: this was asked as an open-ended question; due to the lack of specificity, it is possible that this number is higher and that there may have been more participants who lived with their child). The age of children with psychosis ranged from 18-39 years old (median age = 25 years).

The sample was largely homogenous. All 30 participants self-identified as White and indicated that the U.S. was their country of origin. Of the 30 participants, 23 identified as a caregiver to their child; four did not identify as a caregiver, and three were unsure about their caregiver status. Regarding socioeconomic status, the sample

reported a broad range of incomes: 10 participants reported incomes over $124,000 per year, 10 reported incomes above $84,000, but below $124,000, and nine indicated incomes below $84,000 per year (all before taxes). Twenty participants were employed full-time; two were employed part-time, seven were retired, and one did not respond to the question.

The length of their child's illness varied among parents. Of the 30 participants, five reported their child's illness as less than one year; two reported more than a year, but less than two years; eight reported more than two years, but less than three years; seven more than three years, but less than four years; eight reported more than four years but less than five years. Of the participants, 14 parents reported that their child had experienced civil commitment. Regarding formal support, 16 of the 30 participants reported accessing a support group (such as NAMI), family therapy, or individual therapy). Regarding informal support, all participants except for one reported that they had friends or family as informal support.

Procedure

This study was approved by the University IRB prior to recruitment. A recruitment flyer was then sent to numerous early psychosis listservs and NAMI state chapters. The flyer included eligibility criteria and an electronic link to the survey. Upon clicking this link, potential participants were first asked if they identified as a parent of an adult experiencing psychosis (a schizophrenia spectrum disorder). If the individual clicked "yes", they were then asked if their child had been experiencing psychosis for five years or less. If they affirmed both questions, they were deemed eligible. Individuals were then given an electronic version of the informed consent. Included in the informed consent was information about their rights as research participants, including the right to terminate participation at any point in the study. Participants were also given information

about the survey items and informed that upon completion of the survey they could enter a raffle for a $20 Amazon gift card.

After agreeing to take part in the study, parents were then asked demographic information about themselves and their child, as well as about their experiences being a parent of a child with early psychosis. Participants completed measures including the Mental Illness Version of the Texas Grief Inventory (MIV-TGI), the Parent Child Affectional Solidarity Scale (PCASS), a boundary ambiguity scale, the Intolerance of Uncertainty Scale (IUS), and a depression measure (Center for Epidemiologic Studies: Depression scale). The survey took approximately 20 minutes to complete.

Description of Measures

Parent Child Affectional Solidarity Scale

To measure parent relationship quality, I used the Parent Child Affectional Solidarity Scale (Silverstein & Bengtson, 1991). The Parent Child Affectional Solidarity Scale (PCASS) is one of few measures that has been used to assess relationship quality from the perspective of the parent with an adult child. This measure contains five questions about parents' perception of their relationship with their child (e.g., "How well do you feel you understand your child?") and five questions about how their child perceives their relationship with their parent (e.g., "How well do you feel your child understands you?") on a Likert response scale rated from *not much at all* (1) to *extremely much* (6). Scores were summed and, in this sample, ranged from 23-54. Reliability of the PCASS in this study was strong (α=.89).

Mental Illness Version: Texas Grief Inventory (MIV-TIG)

This inventory was adapted from the Texas Inventory of Grief (Miller et al., 1990) to specifically measure the experience of grief in family members of individuals with mental illness (Miller et al., 1990). There are 16 items that measure a family member's current experiences of grief rated on a Likert response scale of *completely false* (1) to

completely true (5). Examples of items include: “I very much miss the way my family member used to be” and “I cry when I think about my family member.” Scores were averaged and, in this sample, ranged from 1.38-4.63. Reliability of the MIV-TIG in this study was strong (α=.93).

Boundary Ambiguity Measure

This measure was adapted for use with parents of adults with early psychosis from the Boundary Ambiguity Scale for Caregivers of Patients with Dementia (Boss et al., 1990), by omitting one phrase on item number seven. The original item read: “I’m not sure what I should expect _____ to do around the house.” In this study, I omitted the phrase, “around the house” as not all participants may have been living with their child. From my research, there has only been one dissertation research study that used this measure in a study about family members of people with mental illness (Beley, 1991) and I could not find any research that used this measure with parents of adults with early psychosis.

There are 14 items in the Boundary Ambiguity Scale for Caregivers of Patients with Dementia that are rated on a Likert response scale ranging from *strongly disagree* (1) to *strongly agree* (4). Participants could also indicate they were *unsure* (5) about items. All items marked as *unsure* were not included in analyses; no participant had more than one item rated as *unsure*. Examples of scale items include: “I have no time for myself” and “I am not sure how my family member fits in my family.” Scores were averaged and ranged from 1.14 to 3.57. Reliability of the boundary ambiguity measure in this study was strong (α=.84).

Intolerance of Uncertainty Scale

The Intolerance of Uncertainty Scale has been used widely, but never with a sample similar to the one in this study (Carleton et al., 2007). However, there is evidence that a similar phenomenon called the “need for closure” (Onwumere et al., 2009, p.159)

exists in caregivers of individuals experiencing psychosis. This measure has most often been identified as a measure of anxiety, both prospective (future-oriented) and inhibitory (present-oriented). There are 12 items rated on a 1 to 5 Likert response scale ranging from *not at all characteristic of me* (1) to *entirely characteristic of me* (5). Examples of items include: “Unforeseen events upset me greatly” and “The smallest doubt can keep me from acting.” Scores are summed and can range from 12-60. In this sample, scores ranged from 13-55. Reliability of the Intolerance of Uncertainty scale in this study was strong (α=.92).

Center for Epidemiologic Studies: Depression Scale (CES-D 10)

This scale has been used extensively with non-clinical populations (Radloff, 1977) and caregiver populations (Andreson et al., 2013) to assess depression. There are 10 statements for which participants rate how frequently they have experienced x in the last week. The Likert response scale ranged from *rarely or never* (0) to *most or all of the time, 5-7 days* (3). Example items include: “I was bothered by things that usually don’t bother me” and “I had trouble keeping my mind on what I was doing.” Andreson et al. (2013) found that that the CES-D 10 had acceptable alpha levels in three different test groups ranging from .86-.88. In this sample, the CES=D 10 reliability was .83.

Data Analysis

I conducted all analyses on *IBM SPSS Statistics* utilizing version 27 (IBM corp., 2021). My preliminary analyses included examining descriptive statistics (means and standard deviations) of the overall distribution of the primary variables including the parent child affectional solidarity scale, intolerance of uncertainty, boundary ambiguity, and grief. All variables were determined to be normally distributed based on the examination of histograms. I then examined the dataset for possible covariates. Due to the homogeneity of the sample, gender and race/ethnicity were not possible covariates. Other possible covariates were explored by determining their statistical relationship with

the main predictor of parent relationship quality and the outcome of parental grief. These possible covariates included parent age, length of illness, living situation (with parents or not with parents) and civil commitment status. No statistically significant associations were found between these variables and parent relationship quality or parental grief. No statistically significant associations were found between these variables and parent relationship quality or parental grief. In addition, I examined the mean scores of grief and depression for both parents who received formal support (e.g. individual counseling, group counseling, family counseling or NAMI support group or other formal support group) and there were no statistical differences between these two groups.

To test for hypothesis one, I conducted bivariate correlations between parental relationship quality, boundary ambiguity, intolerance of uncertainty, and parental grief. To test for hypothesis two, I conducted hierarchical multiple regressions of three models to predict parental grief. All predictor variables, parental relationship quality, boundary ambiguity, and intolerance of uncertainty, were mean-centered. The first model only included parental relationship quality and parental grief. The second model included boundary ambiguity in addition to parental relationship quality in predicting parental grief. The third model included intolerance of uncertainty in addition to parental relationship quality predicting parental grief.

Prior to the regression analyses, the data set was determined to meet the necessary statistical assumptions. Histograms of each variable were inspected for normality. Consistent with this sample of parents who were in the first five years of experiencing their child with early psychosis, the measure of grief skewed high. To assess for homogeneity of variance, the residuals were inspected and found to be evenly distributed. Bivariate scatterplots and curve estimation regression models were evaluated for linearity. Multicollinearity was evaluated using bivariate correlations and the Variance Inflation Factor (VIF) within the regression model. Intolerance of uncertainty

was found to borderline acceptable, but given the small sample was considered acceptable.

Results

To provide an overall sense of individual variables in this sample, means and standard deviations of study variables are provided in Table 1 and correlations between study variables are provided in Table 2. As predicted in hypothesis one, there was an inverse correlation between parental relationship quality and parental grief such that increases in parental relationship quality were associated with decreases in parental grief (r=-.41, p=.026). There was also a high and statistically significant correlation (r=.79, p<.001) between parental grief and parental boundary ambiguity. However, there was a small and not statistically significant correlation between parental grief and intolerance of uncertainty (r=.33, p=.11).

The second hypothesis was partially supported, as is shown in the regression models in Table 3. In the first model, parental relationship quality predicted 16% of the variance in parental grief $F(1,28) = 5.49$, $p = .026$. However, in the second model, parental boundary ambiguity explained an additional 46% of the variance in predicting parental grief over and above parental relationship quality $F(1,27) = 33.05$, p<.001. Finally, in the third model intolerance of uncertainty only explained an additional 1% of the variance over and above parental relationship quality (not including parental boundary ambiguity) $F(1,27) = .43$, $p>.05$, and it was not statistically significant. Post hoc analyses included correlational analyses between parental grief and parental depression. A significant positive correlation between parental grief and parental depression (r=.52, p=.004) was indicated.

Discussion

Findings from this research indicated that for parents of adults experiencing early psychosis, parental-child relationship quality is an important factor in predicting

parental grief experiences. Further, it appeared that when parents experience grief, they also experience significant uncertainty about their role with their child and their child's role in their family (boundary ambiguity). Implications of this research could expand the theoretical understanding of this phenomenon as well as have significant impact on clinical interventions designed specifically for parents of adults with early psychosis.

As predicted, parental relationship quality was negatively correlated with parental grief. This finding appears to support the application of both ambiguous loss theory as well as attachment theory to the experience of grief in parents of adults with early psychosis. First, from attachment theory, parents who reported a strong relationship with their child, despite the changes in their child precipitated by psychosis, experienced less grief than those who lacked this connection. In attachment language, those parents who were able to maintain a mental representation of their child as recognizable, despite the impacts of the psychosis, experienced less of a sense of loss. Moreover, according to ambiguous loss theory, it is a child's psychological absence combined with their ongoing physical presence, which intensifies and complicates a parent's grief (Boss, 2006). Participants in this survey indicated that they were less likely to experience grief when they experienced a present connection with their child. Thus, the combined psychological and physical presence of the child allowed parents to experience less grief even during a significant change in their child.

An additional finding that supports the application of ambiguous loss theory is displayed in the high correlation found between boundary ambiguity and grief. At first glance, it would appear that this high correlation indicated multicollinearity. However, upon closer inspection of the items, I found that these constructs appear to be measuring different facets of the grief experience. The grief measure (MIV-TIG) examined the intensity of a family member's reaction to the loss (MIV-TIG) by asking individuals to rate statements such as "I can't avoid thinking about ____" or "I cry when I

think about _____" (Miller et al., 1990). These items distinctly ask the family member to reflect on their own internal experiences of grief. Differentially, boundary ambiguity examined the degree of parents' uncertainty about their role in the child's life, as well as the role of the child in the family (boundary ambiguity). Examples of questions measuring boundary ambiguity included "I'm not sure how ____ fits into our family", "I feel like I have to put ____ needs ahead of my own", and "I often feel mixed up about how much I should be doing for_____" (Boss et al., 1990). Parents of adults with psychosis experienced losses related to the uncertainty they had about their own role in their child's life, the child's role in the family, and a loss of their own independence and ability to act independently without having their child in mind. Therefore, grief and boundary ambiguity were two distinct constructs, albeit highly correlated for these parents.

Consistent with ambiguous loss theory, it was parents' boundary ambiguity, or their uncertainty about roles in the family (both theirs and their child's), which was the strongest predictor of grief in parents of adults with psychosis and explained more of the variation in parents' grief than did parents' relationship quality. This makes sense in light of our understanding of the ways that the nature of early psychosis magnifies the experience of uncertainty for parents. Medical professionals often cannot provide families with concrete prognoses related to the psychosis. This lack of concrete knowledge about the illness and an inability to predict their child's future (situational uncertainty) contributes to the ambiguity of the loss which, according to ambiguous loss theory, is likely to cause family members distress (Carroll et al., 2007).

The findings in this study highlight that parents in this sample experienced situational uncertainty and struggled to understand their child's role. Interestingly, the more general affective measure of intolerance of uncertainty (Intolerance of Uncertainty Scale; Carleton et al., 2007) did not explain additional variance in predicting parental

grief. Thus, from this study it did not appear that parents' struggles to manage overall uncertainty was predictive of their grief. Rather, it was parents' specific uncertainty over their child's role in the family that was predictive of parents' grief. Because past research has shown that parental response to early psychosis in their children can have negative impacts on their recovery, these findings offer original and nuanced insights into understanding parents' complicated and emotional responses to their adult children experiencing psychosis (i.e., expressed emotions).

A recent study has pointed to the positive relationship between family member expressed emotions (their hostility or emotional over-involvement) and family member grief (Hinojosa-Marqués et al., 2019); that is, that higher expressed emotions are associated with higher grief. Moreover, the study found that relationship quality between the family and the individual with psychosis impacted the relationship between family member grief and family member expressed emotions. To put it more simply, when family members had a stronger relationship with their family member who was ill, there was a decreased association between grief and expressed emotions. The current study appears to support this by pointing to an association between family members' relationship quality and family members' grief. Given that many of the family members in the Hinojosa-Marques et al. (2019) study were parents and that parents often have a uniquely intimate relationship with their child, learning more about typical manifestations of parental grief will not only benefit the adult child experiencing early psychosis, but also their parents.

Rather than viewing parents' emotions from a pathological perspective, it is important to note that the grief experienced by family members is understandable due to the stress of the onset of psychosis. Moreover, because parents have an especially important and long-term relationship with their child, their grief is uniquely impacted by the relationship they can maintain with their child, and as well as the uncertainty of the

child's role in the family. Therefore, future research that aims to understand parents' emotional response following the onset of psychosis would benefit from including variables related to relationship quality and parental boundary ambiguity.

Limitations and Implications

The limitations of this study are important to note. This is a cross-sectional study and therefore only provides a snapshot of parents' experiences. This means that I cannot draw conclusions about what parents experience over time, and this represents a significant limitation of this study. In addition, the population affected by early psychosis, particularly in the first five years after onset, are under considerable stress as they try to understand the illness and cope with the changes in their lives. For these reasons, participants are often difficult to recruit for studies like this. Therefore, studies on populations such as these tend to employ small, convenience samples that render results ungeneralizable to the population experiencing early psychosis. Sample participants in this study were predominantly White and female. The sample does not reflect the experiences of people of color or parents who do not identify as female. The individuals not included in this sample may have different experiences and perspectives and may likely meet barriers when dealing with the mental health treatment system. Another limitation is a risk of non-independence in this sample, namely that it was possible that two parents from one family responded to the survey. A question was added to account for non-independence soon after data collection started. Finally, two items in the CES-D scale were unintentionally omitted on the survey. Despite this error, the reliability of the measure in this study was good ($\alpha = .83$).

Future research on grief in parents of early psychosis should include larger and more diverse samples. The sampling efforts done here relied primarily on agencies that provided treatment and support for individuals living with psychosis and their family members. Recruiting participants through more diverse pathways to reach individuals

who are experiencing psychosis, such as through educational institutions, religious groups, and/or correctional institutions might expand the possibility of finding participants from a wider range of social locations.

There is a paucity of interventions for parents of individuals experiencing psychosis. Based on this study, it is clear that parents experiencing grief need special attention. Further, interventions for parents should address the relationship quality with their child as well as the uncertainty that parents experience regarding their child's role in the family. Interventions that prioritize helping parents recognize the ambiguity that surrounds their loss and grief experiences may help them cope. Moreover, because grieving parents are simultaneously struggling with uncertainty about the role of their child in the family, interventions based on ambiguous loss theory and its tenets of uncertainty and boundary ambiguity may provide parents support for managing the significant change and stress in their family.

Conclusion

Past research on family of individuals experiencing early psychosis have predominantly focused on a generalized caregiving experience (Cairns et al., 2015; Dilinger & Kersun, 2018; Onwumere et al., 2017) and expressed emotions (Hinojosa et al., 2019; Izon et al., 2020). In this study, there was evidence that not all parents of adults experiencing psychosis see themselves in a caregiving role, yet they all occupy the weighty role of parent. Because parents often have a history with their child and play pivotal caregiving roles in early childhood and adolescent years, the changes in and influence of the parent-child relationship as their adult child experiences psychosis needs continued study.

Research on families of adults experiencing early psychosis has documented how relationship quality may impact the association between a family member's expressed emotions (their hostility or emotional over-involvement) and their grief

(Hinojosa-Marques et al., 2019). Results from this study add to the extant body of literature on early psychosis and highlight the importance of relationship quality and how it influences parents' ability to engage with the uncertainty, loss, and grief that inevitably emerge from and surround the onset of early psychosis in their child and their child's life trajectory.

Parents play an important role in their children's access to mental health treatment (Onwumere, 2018). Research has shown that family support leads to superior treatment outcomes in individuals experiencing early psychosis (Hooley et al., 2007). Therefore, it is essential that future research examine how parents respond to and cope with this stressful first-episode psychosis that their child is experiencing. Findings from the current study, grounded in attachment and ambiguous loss theories, provide new directions for the development of supportive family interventions that attend to parents' grief, their relationships with their adult children, and the ambiguity of parents' losses when their adult child experiences first-episode psychosis.

Chapter 3

The Nature of Grief in Parents of Adults Experiencing Early Psychosis

The experience of psychosis often occurs at a turning point in development when both children and their parents are already experiencing changes in their family roles and how they relate to each other. When psychosis arises, it creates significant disruptions to these normative developmental processes. Past studies on the family response to chronic schizophrenia have shown that family members often grieve the changes in their loved one experiencing psychosis (Richardson et al., 2011; Williams-Wengerd & Solheim, 2021). Unfortunately, research on the impacts of early psychosis on the family has focused predominantly on the experiences of caregivers of adults with early psychosis as a homogenous category, without distinguishing the roles of family members such as sibling, parent, or grandparent.

There is evidence to show that the changes precipitated by psychosis can be particularly impactful for parents due to the unanticipated shift in their parental role (Godress et al., 2005; Stein et al., 2013). As children grow and mature, they often seek to increase their independence and autonomy. Similarly, parents typically anticipate a decline in their need to provide care. However, their child's early psychosis often thrusts them back into a caregiving role that parents had anticipated was diminishing. Parents may grieve for the difficulties their adult child is experiencing, as well as for the changes in their own expectations for their children. Parents may also grieve for their own difficulties related to caregiving and the changes in expectations for themselves as they experience ambiguous and unexpected shifts in their parenting role.

Past research shows that early intervention for individuals experiencing psychosis is critical (Dixon et al., 2015; Mueser et al., 2015), and that families can play an influential role in the long-term prognosis of the mental illness (Claxton et al., 2017;

Iyer et al., 2020). Although it appears that grief is a common experience in families of individuals experiencing early psychosis, little is known about parents' grief experiences (Patterson et al., 2005; Stein et al., 2013; Williams-Wengerd & Solheim, 2021). Therefore, it is important to expand and deepen the understanding of parents' experiences of grief in the early stages of psychosis to fill the current gap in the literature.

Utilizing hermeneutic phenomenological methodology, I found that parents' lived experiences of grief were permeated with considerable uncertainty about changes occurring in their child, their relationship with their child, and their own role in their child's life. As parents struggled to understand how psychosis impacts their child, their relationship with their child, and their own role, they experienced overwhelming emotions including feelings of sadness, fear, guilt, and anger. The changes due to their child's early psychosis created situations in which parents were faced with continual choices imbued with a complex paradox of holding on and letting go of their child as they had understood them to be, of their relationship with their child, and of their understanding of their parenting role. Key concepts from life course (Aldous, 1990; Cook et al.,1997; George, 2007) and ambiguous loss theories (Boss, 1999, 2006, 2016) provided a scaffolding for understanding the complex phenomenon of their grief. The study's findings have important practical implications for how clinicians can support parents of adults with early psychosis.

Background

Past research shows that having family members engaged in early psychosis treatment can improve outcomes for individuals experiencing early psychosis including a reduction in symptoms (Claxton et al., 2017), increases in treatment engagement (Iyer et al., 2020), and a reduction in relapse of psychosis (Camacho-Gomez & Castellvi, 2020). Moreover, it appears that family engagement in treatment for early psychosis can

improve outcomes for family members, specifically reduced caregiver burden and improved psychological and physical well-being (Claxton et al., 2017; Oluwoye et al., 2020).

There is also evidence that families' responses to their loved one living with psychosis can have a negative impact on the loved one's recovery; namely, families who exhibit expressed emotions (such as criticism and emotional over-involvement) are more likely to have a loved one who has increased relapses or increased psychiatric hospitalizations (O'Driscoll et al., 2019; Koutra et al., 2014; Onwumere et al., 2011). Past research has also shown that caregivers of individuals with early psychosis experience grief in response to their loved one experiencing early psychosis (Mulligan et al., 2013) and that this grief is associated with expressed emotions such as emotional over-involvement (Patterson et al., 2005). More specifically, research on parents of individuals with serious mental illness (e.g., schizophrenia) shows that parents experience grief (Godress et al., 2005; Miller et al., 1990; Stein et al., 2013; Williams-Wengerd & Solheim, 2021) or a sense of loss over who their child was prior to the onset of psychosis (Richardson et al., 2011).

In the past 20 years there have been increased efforts to intervene early in psychosis treatment (Dixon et al., 2015; Mueser et al., 2015). Although these efforts have included a family education component (as seen in coordinated specialty care; Mueser et al., 2015), there has been a lack of research exploring the unique experiences of parents of adults experiencing early psychosis. Rather, in the extant literature on early psychosis, the focus has been more generally on family or caregivers without recognizing the person's unique role. Typically, from birth to adulthood, parents emotionally invest in their children and develop relationships which are unique and enduring. Moreover, there is a developmental trajectory for parent-child relationship that

mirrors the child's developmental growth. As the child grows and matures, the role of the parent changes.

The onset of psychosis often interrupts this shift in roles whereby parents are pushed back into a more intense caregiver role that has increased complexity. Parents must adjust their previous expectations of their child's increased independence and autonomy and accept their child's reversion to increased dependency. Although past research on schizophrenia has shown that parents experience grief (Marsh & Johnson, 1997; Wiens & Daniluk, 2009, 2017), studies examining the phenomenon of grief in the early stages of psychosis has not specifically or explicitly focused on the *nature of parents'* experiences. Family development and system's theories such as life course theory and ambiguous loss theory, suggest that the nature and timing of the onset of early psychosis will affect parents and their adult children in distinctive ways. Thus, this study aimed to understand the phenomenon of the nature of parents' grief when their adult child experiences early psychosis.

Theoretical Foundation

Life Course Theory

Because psychosis most often presents in early adulthood/late adolescence, life course theory provides a valuable lens for understanding how the onset of psychotic symptoms impacts not only the individual with the illness, but also their parents (Aldous, 1990; Cook et al., 1997; George, 2007). Life course theory is grounded in the assumption that timing, context, interdependence, and culture all impact the family (Allen & Henderson, 2017; George, 2007). Individuals with early psychosis are typically in a life stage characterized by increased independence and autonomy from family. Additionally, young adults often seek close relationships outside of their family and typically explore educational and/or vocational opportunities that allow them to be more independent. Parents of young adults experience simultaneous changes associated with middle

adulthood as they reflect on their contributions to family and society and hope their contributions will have a positive impact on future generations. Parents and children also experience changes in their relationship when their young adults are “launched.” Parents typically anticipate their parental role will include less caregiving, and their adult child anticipates gaining independence.

Psychosis often disrupts the typical tasks associated with young adults’ developmental stage. In these situations, developmental tasks may not be completed, or young adults may regress to earlier stages of development. Reciprocally, these disruptions affect parents’ understanding and enactment of their own parallel developmental tasks. The concept of “linked lives” in life course theory captures this interdependent set of disruptions and changes (George, 2007, p. 194). Thus, even if an adult child is not living in their parents’ home, their health and well-being affects their parents and other family members. Research shows that families, specifically parents, are highly impacted by the onset of mental illness and early psychosis, as indicated by added caregiving roles, increased stress, and decreased well-being (Godress et al., 2005; Onwumere et al., 2019; Stein et al., 2013). Because parents are expecting a diminished caregiver role after launching their child, they face an unclear situation regarding their role in their child’s life. Although their child may legally be an adult, parents may feel compelled to expand their parenting role by taking on caregiving tasks they thought were no longer needed.

Family Stress and Ambiguous Loss Theory

The stressor of psychosis on the family is not a clear or fixed precipitant; rather, psychosis often changes in intensity and could be limited to only one episode or persist for many years (Fusar-Poli et al., 2017). Thus, while the traditional family stress and resilience model provides a way for understanding stressors that occur over time which may result in “stressor pileup,” it is less informative when understanding a stressor as

uncertain and unpredictable as psychosis (McCubbin & Patterson, 1983, p.11). Ambiguous loss theory provides a relationally-informed lens through which to understand a unique type of stressor; a loss that is filled with uncertainty and lacks clarity (Boss, 1999, 2006). Parents, who have known and cared for their child for many years may experience a sudden change in how their adult child acts and relates to them following the onset of psychosis. Further, there is often ambiguity about the diagnosis associated with the onset of psychosis (e.g., whether or not it is substance induced; whether it is a brief psychotic disorder, schizoaffective, or schizophrenia, etc.).

Parents may not initially notice or identify that their child is experiencing mental health symptoms (i.e., the prodromal period). Although not all individuals experience a prodromal period, it is typically a period of time before the acute onset of psychosis when individuals experience social withdrawal, increased depression, and/or anxiety (Yung & McGorry, 1996). Parents may understandably attribute these symptoms to typical adolescent behavior rather than signs of a more serious illness. Further, if parents do seek treatment from general medical providers, they may not identify the experience as psychosis and/or children may not articulate their psychotic symptoms to a provider. Thus, the diagnosis can be unclear. Adding to the ambiguity is that prognosis is often imprecise; not all individuals experiencing psychosis follow a chronic trajectory. This lack of knowing about the future can be particularly stressful for the family.

Ambiguities surrounding their child's circumstances now and into the future could contribute to parents simultaneously experiencing their child as physically present and psychologically absent, a key tenet of ambiguous loss theory (Boss, 1999, 2006, 2016). Without support to help parents recognize and acknowledge this confusing situation as one involving loss and associated grief, parents may struggle to articulate what is happening with their child and the distress they are experiencing. If parents can develop the ability to tolerate the uncertainty and accept the ambiguity of their losses, it can help

them avoid becoming “frozen” in their grief where they are unable to process their loss experiences (Boss, 1999). According to ambiguous loss theory (Boss, 2006, 2016), if family are unable to process their loss and grief, they are at risk of heightened anxiety and mental health issues.

Purpose

Previous research on families of individuals experiencing early psychosis has lacked a focus on parents’ unique experiences of grief. Although research on parents of adults experiencing chronic schizophrenia and family theory provide support that being a parent contributes to a unique experience of grief, recent research on early psychosis has neglected to specifically isolate and examine parents’ grief experiences. Using a hermeneutic phenomenological approach, I captured the lived experiences of parents of adult children with early psychosis through in-depth interviews. The goal of my analysis of these interviews was to discover the essence of parents’ lived experiences of grief.

Method

Research Design

This study employed a hermeneutic phenomenological design (van Manen, 2015). In hermeneutic phenomenology, the researcher asks open-ended questions with a goal to “unearth something telling, something meaningful, something thematic in the various experiential accounts” (van Manen, 1990, p. 86). The researcher “gathers participant accounts and strives to understand the essence of a complex phenomenon with a primary focus on experiential meanings” (van Manen,1990, p. 11). Throughout the process, it is important that the researcher recognizes, documents, and reflects on their own personal beliefs and attitudes about the studied phenomenon.

Positionality

To this end, it is essential I reflect on my own position and the ways in which my training, education, and experiences impact my data analysis and interpretation. First, I

am trained in counseling psychology and worked for over 13 years as a mental health practitioner and professional. I worked in different treatment settings including residential treatment and in the community. My training in counseling and my role as a mental health professional have informed and inspired my research on parents' experiences. In addition, in the past three years I have been researching and studying ambiguous loss theory and its possible applications to the experiences of parents of adults experiencing mental illness. As a phenomenological researcher, I recognize that my identity as a mental health professional and my educational experiences will impact how I understand these data.

Bracketing

To curb the influence of their identity, a phenomenological researcher uses a process of bracketing, to set their beliefs aside and attend to the essence of the participants' experiences (van Manen, 2015). Although phenomenological researchers recognize they can never fully exclude their own experiences and beliefs, bracketing is a conscious practice by which the researcher works to limit the impact of these beliefs on the analysis. Phenomenological researchers seek to find patterns of concepts or structures that comprise the participants' lived experience and engage in "mining meaning" (van Manen, 2015, p. 86). In this study, I sought to understand the essence of the lived experiences of grief in parents of adults with early psychosis. The primary question asked of participants was: "What is the nature of your grief as a parent of an adult child with early psychosis?"

Recruitment

Following University IRB approval, participants were recruited from multiple mental health support programs, including a listserv developed from a clinic-based first-episode psychosis program. Participants were also recruited from other support programs including the National Alliance on Mental Illness (NAMI) Minnesota, NAMI

Wisconsin, NAMI Iowa, NAMI New Hampshire, NAMI Washington, and PEPPNET (Prodromal and Early Psychosis Program Network). Individuals were included in this study if they identified as parents of adults (over age 18) experiencing psychosis or a schizophrenia spectrum disorder for less than five years.

All individuals in this study were initially recruited to participate in both a survey (n= 30) and/or an interview (n=13). Participants could opt into the interview following their completion of the survey, and over half of the individuals who completed the survey also indicated interest in participating in an interview. To protect participants' survey data, participants were taken to a separate survey to indicate their interest in the interview. All participants who indicated that they were interested in participating in an interview were then contacted via email. Participants were given a link to the informed consent where they were given more detailed information about the interview. Participants were asked to complete the informed consent which also inquired about participants' willingness to have their interview video recorded. Participants were free to opt out of interview recording. All individuals who completed the informed consent were contacted via email to set up a time to meet over Zoom. Twenty participants expressed an interest in participating in the interview; however, some participants did not respond to emails. Consistent with previous qualitative research on family response to early psychosis (Cairns et al., 2015) and given the exploratory nature of the research, I set an a priori goal to interview 10-15 parents (Vasieleiou et al., 2018). I found that saturation of data became apparent after 13 interviews where it appeared that interviews became repetitive, and I obtained no new information about parents' experiences.

Sample

A final purposive sample of 12 mothers and 1 father, all of whom identified as parents of adult children experiencing psychosis for less than 5 years, participated in this phenomenological study. I have provided additional information about the sample in

Table 4. Demographic data gathered in the survey revealed that this sample was highly homogenous, with 100% of participants having identified as “White.” Some demographic data were gathered in the interview process; all interview participants indicated that they had a partner or spouse and 77% reported that they had a college degree or higher (10 out of 13).

Data Collection and Transcription

I conducted 45-90 minute interviews over Zoom. After affirming consent, I shared a brief introduction and described what the interview would entail. I asked participants if they had any questions and clarified their comfort regarding the recording of the interview. Ten of the 13 participants, despite assurances of confidentiality, agreed to have their interviews recorded. I took handwritten notes for the remaining three interviews. I began the interview with a broad question about participants asking them the question, “Can you tell me about yourself?” (see Appendix B for the full interview script.) I concluded the interview by asking participants for any advice they would have for other parents of adults experiencing early psychosis. Finally, I thanked them for their participation and provided them with information about my plans to email them their transcripts and/or interview summaries for their review. All individuals who engaged in interviews were given a $20 Amazon gift card in exchange for their time.

I transcribed all recorded interviews via the Zoom auto-transcript function. Participants were emailed their verbatim interview transcripts as well as a brief summary of the interview. The three participants who did not agree to record their interviews were emailed the summary only. Participants were invited to give feedback via email on the accuracy of the transcription and the interview summaries. I received feedback from six of the 13 participants (46%). Feedback from five participants included brief comments on the transcripts and/or additional information about their experience. One participant provided extensive additional details related to their transcript. In alignment with van

Manen's (1990) methodological guidelines that participants should actively engage with the researcher throughout the process, their feedback and additional information was also considered data to be included in the analysis stage.

Data Analysis

Data in this study included interview transcripts, interview summaries, research memos, and member check communication. I was guided by the hermeneutic phenomenology methodology, which is an organic process involving a continuous return to the research question throughout the analysis of participant accounts. I started the data analysis process by reading the interviews and interview summaries. I then conducted line-by-line coding, guided by the question "What is the nature of parents' grief experiences?" I extracted meaningful quotes that described the phenomenon and wrote a description of these quotes adjacent to the quote for each interview and subsequently wrote an interview summary in a Word document. An example of one of the meaningful quotes that I extracted was:

> because when, you know, I think we're having like a good day and then or, you know, I can kind of see there's times, where I know, like, she's somewhere else, like her, the way she looks and the way she can't hear me, so a lot of times I get her attention I say [daughter's name] and somedays she goes on a rant of her horrible dream . . . and of course, it affects me and I want to do more for her, but then I might think am I coddling her too much. Should I be like pushing her or . . .?

This statement captured how this parent was experiencing *changes in her child*. I found multiple examples of participants' descriptions of *changes in their child*. As I read these quotes that centered on this idea, it became clear that *changes in one's child* was a meaning structure (van Manen, 2015) that was an integral part of the lived experience of parents' grief.

Another example that stood out for me was *unpredictability.* One of the first quotes that I extracted about this meaning structure was:

> That was the start of it and it probably was started before that, but that was the first episode, because she would she did tell me, 'Oh, when I was in my apartment I would go sometimes two days with like weird dreams' and these were thoughts but nothing was connected beyond her like creative thinking, but I maybe could have seen signs before if I would have known what I was looking for.

After I completed compiling the quotes that captured these meaningful structures in all 13 transcripts, it became clear that the essence of parents' grief came from three types of losses: losses related to child, losses related to parents' relationship with their child, and losses related to parents' own role.

It also became clear that the nature of parents' experiences of grief were consistent with a definition of grief found in past literature. This process was consistent with van Manen's (2015) instruction to phenomenological researchers to interrogate literature to inform their analysis process. Grief has been defined as a "cognitive, behavioral, and emotional reaction to loss" (Davis & Schultz, 1998; Godress et al., 2005, p. 88). Using this definition, I proceeded to code parents' meaningful statements as "losses", "emotions", "thoughts", and "behavioral responses." I then grouped the quotes based on these codes and conducted coding across transcripts to understand the essence of each of these codes and how they answered the research question, "What is the nature of parents' grief experiences?"

I met numerous times with my advisor to engage in what van Manen called "collaborative analysis" (van Manen, 1990, p. 100-101). Collaborative analysis involves another researcher reading the text to "engage in dialogue and questioning, to allow the author to see the limits of her current interpretation and formulate deeper meanings and

underlying themes" (p.100-101). During our meetings and throughout the cross-case analysis, I found three overall themes that consistently emerged. It is important to note that throughout the data analysis process, I consciously and repeatedly set aside my understanding of both ambiguous loss and life course theory. Rather, at this and previous stages, I attended to the lived experiences of the participants to better understand the nature of their grief experiences. I provide an example below of how I bracketed (set aside) my understanding of boundary ambiguity during analysis. To be clear, these bracketed notes were not included in my analysis:

> Appears consistent with boundary ambiguity where there are two tasks: (a) Navigate their role with the child (what can do for the child, what can child do for themselves), but this isn't necessarily in isolation; and (b) also how the child fits in the family (this can definitely not be done in isolation).

To address methodological rigor and trustworthiness in my qualitative analysis, I relied on the recommendations of Anfara et al. (2002), who noted that researchers must address: credibility, transferability, confirmability, and dependability. To address transferability and dependability, I utilized triangulation by analyzing the interview transcripts, reflective memos, and coding of the data. To provide evidence of credibility, I engaged in member checks by providing participants with interview transcripts and summaries of the interview. Six participants actively engaged in the member checking process by providing me with additional information about their experiences. An example of this exchange of information is a parent who informed me that they found that their grief had decreased in intensity as their child's illness had lessened.

To further address transferability, I engaged in purposive sampling by only interviewing parents of adults experiencing early psychosis as indicated in my methods section (Anfara et al., 2002). This assured a common window of time (the first five years after onset) during which all parent participants experienced grief. I also have provided

thick descriptions of participants' experiences by using extensive participant quotations. To address dependability, my advisor and I engaged in collaborative analysis involving a review of my transcripts and engagement in discussion that helped me consider potential limitations in my interpretation and deeper meanings of participant accounts. To address confirmability, I briefly shared my positionality as a researcher earlier in the methods section (and included a lengthier positionality statement in Appendix C). I also utilized reflexive memo writing, documenting my reflections on data interpretation throughout the research process as a way to bracket my experiences as a mental health professional and my knowledge and use of ambiguous loss theory. Finally, I met with a colleague (a family peer specialist who works with families experiencing early psychosis) who is also a parent of an adult child experiencing psychosis, to discuss my data analysis and receive feedback based on her lived experiences. She indicated that my results were consistent with her work with families and her own experiences as well.

Results

The goal of hermeneutic phenomenological methodology is to understand the essence of human lived experience (van Manen, 1990, 2015). Although I identified multiple themes that captured an aspect of the nature of parents' grief, it is important to note two general observations about the experiences of the participants involved in this study. First, all parents in this study affirmed that they experienced some type of grief following the onset of early psychosis in their child. This is not surprising because parents were informed that the study was on parents' experiences of grief. Moreover, the purpose of this study was not to determine if grief existed, but rather to understand the nature of the grief experiences in parents of adults in the early stages of psychosis.

Second, parents' experiences of grief varied both among and within individual parents, meaning that while some parents described intense daily sadness, other parents did not. Parents' individual grief experiences also often varied day to day, week

to week, and/or month to month. One parent described how they had “good days and bad days” and that these “can occur in quick succession.” Some parents noted that their grief was more intense at the onset of the psychosis but had generally decreased over time, while other parents noted a more cyclical nature to their grief. Others indicated that their grief was greatly impacted by the severity of their child’s symptoms, which were dynamic and changed both for better and worse over time.

The Nature of Grief

For this sample, the experiences of grief were not described as discrete events. Rather, parents described their experiences as dynamic, interconnected, and complex. The three themes I found included parents’ uncertainty, a paradox of holding on and letting go, and parents’ overwhelming emotions. As I focused on discovering the meaning structures that evolved into these three themes, I noticed that there were three threads that ran through the themes which wove in an important layer of complexity. The three threads of interconnected domains related to their losses included: (a) the loss of their child as they had once known them and the related losses their child was experiencing due to their early psychosis, (b) the loss of their parent-child relationship due to their child’s early psychosis, and (c) the personal losses, including their role as a parent which resulted from their child’s early psychosis. These findings are described in Table 5.

Further, a temporal dimension was infused throughout parents’ grief experiences. They described current experiences of grief and reflected on things from the past, including their concerns that they may have ineffectively parented their child or what *clues* they missed that might have helped them notice their child’s path toward psychosis. They also projected into the future about whether they would continue to feel anxious and worried, if uncertainty and unpredictability would be there the rest of their lives, and how long they would continue to struggle with holding on and letting go.

Theme 1: Uncertainty

Uncertainty: Where is my child?

The most pervasive theme that transcended all parents' experiences of grief was their uncertainty. The interviews clearly reflected parents' struggle with uncertainty about their child's illness, the losses that they experienced from their child's psychosis, and how to best respond to their child. Parents' experiences of uncertainty existed in three overlapping domains: their child, their relationship with their child, and their response as a parent. However, it was clear that these losses could not be disentangled.

A temporal dimension was also evident in parents' uncertainty regarding their child's illness. As parents reflected on the past, they simultaneously braced for the future. Parents described their experiences of uncertainty about the present condition of their child with questions such as, "Where is my child?" or comments such as, "I don't know who this person is." Many parents indicated that the shock of the psychosis was worse for them at the time of initial onset. Molly (note: pseudonyms are used for all participants), a mother of a son experiencing psychosis for four years, described the experience of uncertainty and shock at onset by stating:

> It was [his] senior year when it really went bad and he clearly was having a psychotic episode and it was when we fully knew it, but we didn't know what it was, but we're just like "What the hell?"

Parents talked about how the onset of psychosis precipitated changes in their child's behavior and personality. They shared examples of changes in their child including confusion, paranoid thoughts about others or people in the family, and/or becoming threatening or violent towards family members. Many parents described their children engaging in activities or acting in a way that was not consistent with who they were prior to the psychosis. Gloria, a parent of a son experiencing psychosis for five years, described an incident just following onset. She went to pick him up from college

and he tried to open the car door while she was driving at 70 miles per hour on the freeway. Another example is Harriet, a mother of a son experiencing psychosis for the last four years, who described how her child who had previously been very mild-mannered prior to the onset of psychosis later threatened her with a knife.

Although many parents described intense shock at the onset of psychosis, they also indicated that the experience of uncertainty of the loss was not confined to onset but had continued over time. Francis, a mother of a child experiencing psychosis for the last two years, stated that her and her husband had "definitely been going through grief. There's a whole lot of like, I miss the old [child's name]." Other parents described personality changes in their child, where they were "prickly" or "mean" which stood in contrast to their child's personality prior to the onset of psychosis.

Parents described abilities that had disappeared since the psychosis began including their child's loss of ability to do tasks (such as how to use a can opener), the loss of their ability to live independently, or the loss of their ability to engage socially with friends. Parents also described a loss of a sense of safety for their child with a few parents indicating concerns that their child could die as a result of the illness (e.g. by suicide, freezing to death, getting shot by police). Complicating these losses was that their child's physical appearance remained the same. Gloria again noted that, "he's forgetful and you know he's just he's not himself and he has a brain disease, but he looks fine."

Uncertainty about Relationship with Child: What can I Expect?

In the parent-child relationship, parents lamented that they could no longer engage with their child in activities that had once been enjoyable for them because their child was no longer living "in the same reality." Some parents described anxiety about having their child over for dinner or having them attend extended family events due to their child's personality changes. The changes in their child since the onset of psychosis

impacted their ability to maintain a connection with their child because they were no longer able to engage in past activities (e.g., camping, traveling). Complicating this further was the inconsistency or unpredictability of their child's behaviors. Parents described how they never knew "who" would show up. This unpredictability fueled their experience of uncertainty about their child and their relationship with their child. Anna, a mother of a daughter experiencing psychosis for the last three years, described the difficulty of maintaining a connection with her child when she stated, "because when you know I think we're having like a good day and then or you know I can kind of see there's times, where I know like she's somewhere else, like her, the way she looks and the way she can't hear me."

Parents' experiences of uncertainty about their child and their relationship with their child in the present or recent past were often linked to their wondering if they had missed previous evidence of the child's illness or if they had done or not done something that could have contributed to the illness. Emma, a mother of a son experiencing psychosis for four years, shared:

> I mean you know when you're you know there's always like what could, we have done differently?" [starting to cry] what could or what, how could we have, you know that's the part you know you're you blame yourself, blame each other all the time. I think awhile back and we're not you know, make the, how could we make things different?

Parents described uncertainty about present losses triggered by their child's illness and how this led to a significant change in their expectations for their child's life. Harriet described the psychosis as a "death of dreams" for their child, and Jessica, a mother of a son experiencing psychosis for the last two years, stated:

> But I think the grief comes in, because again from the perspective of that sort of the trajectory that he was on prior to all of this happening was we had no reason

to think that he wasn't going to sort of take a more traditional path and whatever that meant to him.

The uncertainty was not merely based on their present experiences with their child; even when their child was doing well, parents continued to experience uncertainty. Francis, a mother of a son experiencing psychosis for two years, stated, "Yeah, and even when he's doing better you still keep looking over your shoulder, wondering if that's gonna stay, you know, there's also you know that anxiety."

Uncertainty: How do I Parent?

Parents also described the uncertainty of how they understood their role with their child. Parents had not anticipated an expanded caregiving role in their child's life at this stage, and this expanded role of caregiving was not easily accepted by their child. Gloria described this uncertainty about her interactions with her son who was experiencing cognitive deficits:

> You know there's times, where I'll explain things to my son and he'll say "Mom, I'm not a child," and I understand that but I'm like, I never know if I'm explaining too much or too little you know so it's a really weird spot to be in.

Jessica stated that they experienced uncertainty around "What do I do? Where do I go? Who do I talk to? How do I help him?" She described how she had tried various techniques for responding to her child when he was psychotic, but she continued to struggle to know how to best respond to him. Betty, a mother of a son experiencing psychosis for the last three years, described her confusion about how to encourage her adult son to take medications. She stated, "You know to get him to agree to what we know he needs to do and sometimes it works, sometimes it doesn't."

Parents shared that the uncertainty they felt about the change in their caregiving role due to the early psychosis had impacted other roles in their life. For some, it decreased the time they spent with friends. Francis stated, "I mean I still work hard to try

to like, you know, I still see my friends, but I'm not as engaged for the happy person to the group who supports everyone else, and I'm not that person anymore . . .." Ivan, a father of a son experiencing psychosis for the last two years, similarly described his struggle with friends. He noted that he had to learn which of his friends he could and could not talk to about his son's illness because some of his friends could not *understand* the psychosis.

Parents also mentioned how their uncertainty impacted maintaining their job and balancing their relationships with spouses and other children. Jessica described how she was grateful she had a job that was flexible, so she could be with her son and help with his treatment. Gloria described how she did not feel comfortable leaving her son alone:

> I do live life differently, like you know I said this at a NAMI meeting to I said, you know there's a lot of times, where you know we don't have a gas stove or I'd be more concerned but there's times, where you really don't want you know our son to be alone in the house yeah he's forgotten to turn off the burner on the electric stove which is not a big deal . . . like my husband and I have only went on a two or three you know real vacations just him and I and there's no way and it's only been for a night or two I don't think we would be comfortable going, you know, a far distance.

Gloria went on to also describe how she was also uncertain leaving her son at home with their other children. She stated about her younger children:

> I don't want to put them in a compromising position. You know, it was at the last time he got upset and you know he just exploded and got very angry about something you know very inconsequential with my younger son and you know my son living with the illness got very mad and punched a big hole in the wall and said next time it's going to be you.

In this quote Gloria described how she was put in a challenging position between both her other children and her son with psychosis. Similarly, Emma indicated that she also had experiences of uncertainty which had required her and her spouse to navigate the psychosis together and that this put a considerable amount of strain on their relationship and gotten in the way of her ability to "trust" her spouse.

Theme 2: Paradox of Holding on and Letting go

The essence of parents' grief in this study appeared to reflect their experience of the "paradox of holding on and letting go" to their child, their relationship with their child, and their own understanding of their role as a parent. Parents' overwhelming feelings (sadness, anger, fear, shame/guilt) as well as their uncertainty about their child's illness also contributed to this experience. Their experience of this paradox was strengthened by knowing that their child's situation (including their child's illness, treatment, willingness to engage in treatment) could change at any point and parents struggled to make sense of the past while also preparing for the future.

Paradox of Holding on and Letting go of Child and Relationship with Child

Parents' experiences of both holding on and letting go of who their child was and holding on and letting to go to their relationship with their child were interconnected. Although these themes (their child and parents' relationship with their child) are presented as different domains in Table 5, in parents' actual experiences these domains appeared concurrently. Jessica, a mother of a son experiencing psychosis for the last two years, stated that they:

> try to love the person that you have with you because I mean at some level we all change of course and develop and become different people as we get older and go through different experiences, but this is a fundamental change.

Betty, a mother of a son who has been experiencing psychosis for the last three years stated, "He was amaz- well, there's an aspect of grief to it because he isn't who he

used to be. He was an amazing, exceptional child." She described how the changes in her son had affected her relationship with him, something she sincerely missed:

> It's rough because it's just so different. I feel like that this one I had, God, so I have to learn to love and relate to this new son who is different and it's hard, because he's prickly, and it can be difficult and I've also got to keep, you know, I know he's sick, but there's only so much I have to say, you know, I don't have to let him treat me in a way that I'm not comfortable with, because he's sick. And so, it's just, it's harder. We used to do a lot together before he was sick and he used to have a lot of interest in things and it's, it's harder to enjoy that time together. Our relationship has changed, and I miss it.

Gloria was similarly aware that her child had changed. She stated, "And then your normal child isn't normal anymore and you find that, you know normal is just a setting on the dryer." Conversely, parents described the experience of "holding on" to their child by focusing on something she felt had not changed, something she could still hold on to. Jessica shared that their child's "fundamental human needs are still the same so you can still love that person, while you still grieve the loss of the potential for what could have been."

The experience of holding on and letting go of their relationship with their child varied across parents. Some parents believed that this paradox was best lived out by having their child live with them and others by having their child live apart from them. Cassie, a mother of a son experiencing psychosis for five years, described how she had almost decided to move out of her home (where she lived with her son and spouse) due to a violent incident. She told her spouse, "I'm done. I'm not going to live like this." She described how she got a list of apartments and was going to leave if her son was going to continue to live at home. Her son later moved into a residential setting following a hospitalization. She described how her son's move out of their home had allowed her to

continue her relationship with both her son and her spouse. Later in the interview, Cassie described her current relationship with her son when she stated: “This is my son, and I can’t turn him away.” For Cassie, having her child live outside of her home allowed her to be able to hold on to her child (not turn him away) while she was also able to let go of how she understood their previous relationship.

Paradox of Holding on and Letting go of the Role of Parent

The experience of holding on and letting go of their role as a parent to their child with psychosis was complicated by parents’ sense of responsibility for their child and their well-being. Dorothy, a mother of a daughter experiencing psychosis for three years who stated, “That’s the hardest part is knowing how to walk that tightrope of how much do you help and how much do you let a 26-year-old figure it out.” There was no consensus among parent participants on how to walk this “tightrope” regarding housing and caregiving. Emma stated that they had come to a place of realizing, “that you’re not helping this person and it’s just like you got it that whole ‘let go with love.’ We gotta let him go and figure this out.” In this quote she is simultaneously expressing a sense of acceptance and love for her child while also recognizing the limits of her ability to parent her son.

Molly, a mother of a son experiencing psychosis for the last four years, described how she worked to both hold on and let go of her child in order to prioritize her own wellbeing. She struggled to know how much to do for her son and had come to the understanding that “it’s you know, I can’t do it all.” She noted that she visits her child in a residential treatment setting and her child visits her home, but that she had recently reached a point where she was “letting go” of her son by limiting her son’s visits to their home. Molly shared, “I feel like I’m there for him and it’s really hard. You just don’t know what the right thing to do.” Although she described the experience of “letting go”, it was

clear that letting go was a process of struggling internally with the “hold on and let go” paradox. She had to remind herself that she “can’t do it all.”

Emma described how she had to let go of her son by setting a firm boundary about her son living with her. She was clear about her decision, stating:

> I see it’s just like he’s not going to cross this threshold again that you know and that doesn’t mean I don’t love him or I don’t want to see him again but he’s not coming back in our house.

Francis described this struggle of holding on and letting go to her own role with her son:

> So, I do wonder a lot like, “What is my role here?” Do I just sit back and let it deteriorate in front of my eyes? Or what am I supposed to do? So, my role which I’ve told him and told him yesterday because we kind of talked yesterday but it didn’t go great, but I said I’m going to, you know, I’m not giving up with the drug. You have to take your medication. There’s no negotiation about that. I’m going to bother you about your medication.

Overwhelming Emotions

Many parents described throughout their interviews about being overwhelmed with emotion about their child’s experience of psychosis. Lydia, a mother of a son who had been experiencing psychosis for the last two years and whose son had since stopped most contact with her stated, “It’s all I think about.” She continued, “. . . in the back of my mind it’s like even like whatever, no matter what I do there’s always this big thing of carrying around with me.” Parents’ overwhelming emotions included sadness, fear, guilt, and anger. These emotions were experienced in losses associated with several domains of being a parent, including those related to their child, those related to their parent-child relationship, and their personal losses as a parent.

Sadness

The most predominant emotion indicated by parents interviewed was an overwhelming sense of sadness, and they often cried as they shared about their feelings. Parents were sad about the changes in their child in the present and about their child's changed future. Although some parents described their sadness as persistent, stating that they experienced "sadness every day," others said that their emotions changed depending on circumstances.

Molly noted that although there is "a huge sadness when he's around", she went on to describe how her sad feelings had lessened as her son's illness had improved.

> At least it's, it's not as bad, but it's so painful in another way that I can't, it just hits me in the gut because I feel so sad for him and what his future is going to look like.

Emma described that she felt sad about how her son's illness may impact his future: "I think he's still there. I think yeah that's the sad part yeah but really this last he's gotten out . . . I have questioned if will we really ever get him back."

Fear

Parents described a range of fears about how their child's psychosis was affecting their and their child's present life, future, and safety. For example, Gloria described fear about her son freezing to death after he abruptly left their home during a psychotic episode. In addition, Lydia described how her child had become violent with police due to his psychosis and was fearful of future police altercations. Numerous parents also indicated that their children had shared their hopes related to career or having a family prior to the onset of psychosis, but that they and their child were fearful that these outcomes were no longer possible.

Anna shared that she was fearful for her daughter and also concerned about her safety. "Thinking about her future, yeah makes me afraid for her, and also to be honest and selfish, afraid for me." Numerous parents indicated fear in leaving their child alone in

their home and how this impacted how they lived their lives, including changes in the way they worked and how they navigated life with their partners.

Guilt

Feelings of guilt ran through many of the parents' interviews, including their concerns about either doing too much or too little for their child. Anna described how she felt guilty about both past and present behavior: "Right and maybe even like as a parent prior to that, like I try to kind of analyze myself, maybe I was always kind of like hands on and hovering a little bit more." Molly, like other parents, described the guilt she felt about interactions with her child who lived in a residential treatment center stated:

> that I'm not more involved in helping him with his daily, not daily tasks, but trying to get him, I feel guilty where he's living because it's just hard for us to see him living in a house like that.

Anger

Parents described feeling angry with their child. Although she realized that it was not beneficial, Emma described her overwhelming anger this way:

> You know, obviously, when he's acting out, you know I get angry. I get mad . . . though, this is less and less, because I see that it is hurting me more than it hurts him. It hurts my husband too and so that's something . . . I'm doing it for me, you know I may still feel it but I'm gonna try to control it more, because it really hurts me. I feel, sometimes like you know my blood pressure is going up. I feel like, "Oh my God, I'm going to have a stroke or heart attack."

Kerri, a mother of a son experiencing psychosis for three years, described how she felt she was "enabling" her son by allowing him to live with her and her husband. She stated, "I'm fed up" after describing that he and her spouse disagreed about how to respond to her son. She also described frustration about her son's decision-making and that he had declined to participate in religious activities and book studies. She believed

that if only her child engaged in certain religious activities, he could have a life in which he would be able to more fully “thrive.”

Discussion

The findings in this study offer descriptions of the deep meanings intertwined in the lived experiences of parents’ grief when they have a child with early psychosis. Even in the early stages of psychosis, parental grief is not simply related to their child’s psychosis but is highly interconnected to their relationship with their child and their own understanding of their parental role. The nature of grief in the lived experiences of parents involved in this study is shrouded in uncertainty about their child’s illness and what the future holds for both their child and their family. Parents described complex situations fraught with uncertainty. They were continually faced with a paradox of letting go of their child and hanging on to them, of deeply loving their child and wanting to stay connected to them while recognizing that their child may or may not be able to engage in a shared reality with them or other family members. Parents had to hold on to potential possibilities while acknowledging the losses they experienced in their child, in themselves, and in the relationship with their child since the onset of psychosis.
In this study, parents did not respond uniformly to the onset of psychosis, nor did parents describe a stable situation with clear answers.

The complexity of parents’ grief is consistent with past research on family responses to early psychosis (Mulligan et al., 2013; Patterson et al., 2005) whereby family members of individuals experiencing psychosis exhibit intense sadness and grief. The grief that parents faced in this study was similar to past research on families of individuals experiencing serious mental illness (Godress et al., 2005; Stein et al, 2013). The findings also are consistent with studies on “expressed emotions” whereby family members exhibit intense emotions in response to their family member experiencing psychosis (Patterson et al., 2005; Hinojosa-Marques et al., 2019). Expressed emotions

are often described as either “emotional over-involvement” and/or “criticism” (Patterson et al., 2005, p. 59). Although there is evidence to show the negative impact of these expressed emotions on the individual experiencing psychosis (increased risk of relapse and hospitalization), there is also research to show that expressed emotions may be a response to grief. For example, Patterson et al. (2005) and Hinojosa-Marque´s et al. (2019) both found that family members who exhibited higher expressed emotions also had higher and more intense grief. These findings on caregivers are consistent with the interview data gathered from parents in this study who articulated uncertainty and distress about how to best respond to their child experiencing psychosis. Parents described how they felt pressure to both participate in their child’s care (holding on) while also letting their child have independence (letting go).

The current study fills an important gap in the literature on parents of adults experiencing early psychosis. The onset of psychosis is often in the late adolescence-early adulthood stage when parents are often the de-facto supportive family member (Richardson et al., 2011). Parents are emotionally invested and provide care and support for their child, so it would be logical that parents also experience intense emotions about their child’s psychosis and the changes that psychosis could precipitate. Parents in this study struggled with the constant paradox of holding on and letting go. They articulated a struggle to embrace a balanced response between these seemingly opposite experiences. However, at times, consistent with research on expressed emotions (Hinojosa-Marques et al., 2019), it seems understandable that parents may err on both sides of this dialectic where they become critical and frustrated in their holding on (criticism) or alternately feel guilty, afraid, and sad, and thereby become “over” involved in their child’s care (emotional over-involvement).

The phenomenological experience of holding on and letting go was characterized by overwhelming emotions which appeared to be an expression of parents’ grief.

Parents experienced intense angst about how they should respond to their child and the findings of this study appear to show that intense emotions are embedded in parents' grief. Moreover, said findings reflect the need for a family theory that both normalizes parents' struggle and allows them to embrace the complexity of their situation by accepting and tolerating the paradox of both holding on and letting go to their child, their relationship with their child, and their role in their child's life.

Theoretical Applications

Both life course theory and ambiguous loss theory are reflected in this study's findings. From a life course perspective, parents' grief was "linked" with the lives of their children through the origins of the losses (losses related to their child, their relationship with their child, and their own understanding of their parental role). Parents described the grief that they experienced was not only about the changes in their child that resulted from psychosis, but also how these changes had impacted their relationship with their child and how they felt about themselves and their role in their child's life.

The developmental stage of the child and the parent appeared to complicate parents' grief. Parents described that developmentally they were prepared to launch their child into adulthood and simultaneously assume less of a caregiving role in their child's life. Parents were surprised by the onset of the psychosis and that this change had required them to shift their understanding of their child, their relationship with their child, and the role that they had in their child's life. Consistent with life course theory, the unique developmental stage of both the child experiencing psychosis and the parent adds complexity to the experience of grief. What parents had expected from their child and anticipated for their own life had taken a significant shift. Parents experienced an increased role in caregiving, and their child, despite their own desire for independence, was now more reliant on them than they had anticipated.

The findings here also appear to support the application of ambiguous loss theory. The uncertainty that surrounds the loss that parents experienced is a core tenet of ambiguous loss theory. Boss (1999) asserted that losses that have more uncertainty can impede the natural grieving process. Parents described uncertainty about the nature of the illness and their child: “What happened to my child?” They also experienced uncertainty about their relationship with their child in their struggles to connect with their child, noting that their child appeared changed and was more distant, more “mean,” or “prickly” than they were prior to the onset of the psychosis. These changes made it more difficult for parents to connect with their child. Parents also experienced uncertainty about their role in their child’s life. This is evident in their descriptions of being conflicted about how to best support their child (e.g., living situation, monitoring medications). Parents described this experience as a “tightrope” they walked when they didn’t know how to respond to or support their child.

This experience of uncertainty about their parental role is consistent with the concept of boundary ambiguity from ambiguous loss theory (Boss et al., 1990; Carroll et al., 2007). Boundary ambiguity is defined as “a state in which family members are uncertain in their perceptions of who is in or out of the family and who is performing what roles and tasks within that system” (Boss et al., 1990, p. 246). Although parents did not indicate confusion about their child being in or out of the family system, parents did struggle to understand their own role in their child’s life as well as their relationship with their child.

The concept of boundary ambiguity is also consistent with parents’ experiences of holding on and letting go. Parents navigated the losses they experienced due the onset of psychosis in their child by trying to let go of aspects of their child (e.g., their ability to engage in cognitive tasks, their ability to live independently), which were no

longer present while simultaneously trying to hold on to different aspects of their child and their relationship with their child (e.g., learning to love a different child).

A slight modification of one aspect of ambiguous loss theory as it relates to parents' grief experiences is important to note. Boss (1999, 2006) described ambiguous loss as typically characterized by either physical absence/psychological presence or physical presence/psychological absence that leads to confusion about boundaries and family membership. Parents in the current study did not describe their child as being "psychologically absent" where their child was clearly and fixedly not present. Rather, they described their child as being *precariously present*, where their child was continually in and out of psychological absence and presence. This unpredictability of their child's presence exacerbated parents' grief, anxiety, and vigilance. The complexity of early psychosis adds a nuanced application of the presence/absence paradox to ambiguous loss theory whereby adult children with early psychosis can be physically present and unpredictably and precariously psychologically absent or present.

Limitations

This study has numerous limitations that suggest important directions for future research. One limitation was that the sample was very homogenous (White, highly educated, all married or partnered). Due to the condensed timeframe for my dissertation project and the difficulty of locating participants with these unique experiences, I recruited mostly from programs for family members of individuals experiencing mental illness or early psychosis. Although the purpose of a phenomenological study is not to generalize findings, but rather to seek understanding of the lived experience (van Manen, 2015), readers must take care to consider how participants' characteristics affected their lived experiences. Future researchers should explore the experiences of parents of color who may be less likely to seek support from mental health organizations due to multiple factors including but not limited to previous experiences of discrimination

and limited access to healthcare and are likely to have different pathways of care (Oluwoye et al., 2021). Researchers should also work to build relationships with community organizations, including faith or religious communities, where families of color may be more likely to seek support.

Clinical Implications

Researchers and practitioners have pointed to the lack of support for family members of individuals experiencing psychosis (Kopelevich & Buckland, 2022; Onwumere et al., 2018). Findings in this study are of critical importance for clinicians treating individuals experiencing psychosis and their parents. Parents were simultaneously holding on and supporting their child while also letting go and recognizing their child's independence as an adult. From ambiguous loss theory, a situation with this type of complexity is not one in which closure is possible and therefore is not solved by a provider response which is prescriptive and concrete. Rather, it appears that parents are experiencing an understandably emotional and overwhelming situation that is unclear and dynamic.

Ambiguous loss theory, which was designed to reflect how families respond to unclear stressors, provides a framework and language for parents experiencing early psychosis whereby a clinician allows space for the family members to acknowledge and explore their grief. Boss (2006) wrote about numerous therapeutic strategies that can be used to support families experiencing ambiguous loss including ideas such as "normalizing ambivalence" where providers can support and validate the family member's conflicted feelings between what appears to be two opposing positions (e.g., holding on and letting go; p. 148). Future interventions for parents of adults experiencing early psychosis should address parents' grief and employ therapeutic strategies grounded in ambiguous loss theory.

Conclusion

Research has shown that having family members involved in treatment can decrease the risk of unnatural death in individuals experiencing schizophrenia (Reininghaus et al., 2015). Although past research has suggested that the intense emotional expression of family members are risk factors for relapse and further hospitalization (O'Driscoll et al., 2019; Hooley et al., 2007), other research (Patterson et al., 2005, Hinojosa-Marques et al., 2019) supports that families' expressed emotions are an adaptive response to grief associated with changes in their loved one.

Findings from this study offer a deep look into the essence and nature of the grief parents of adults with early psychosis experience. In summary, parents' lived experiences of grief are shrouded in uncertainty. Parents grieve losses for their child, losses for their relationship with their child, and personal losses. They experience intense emotions and struggle with the paradox of holding on and letting go. In this study, parents described how psychosis not only changed their child, but also their own life and relationship with their child. Support for families experiencing psychosis is desperately needed for the well-being of individuals living with psychosis, their parents, and their families.

Chapter 4

Discussion

The critical importance of having family included in a loved one's treatment of early psychosis has been widely established (Camacho-Gomez & Castellvi, 2020; Claxton et al., 2017; Kopelovich & Buckland, 2022; Iyer et al., 2020). This dissertation adds to extant literature with a specific focus on parents' distinct experiences of grief following the onset of psychosis versus the broad examination of familial or non-familial caregiver's experiences as indicated in past research. Another distinction of this dissertation is the use of a family-centric lens. Much of the past research on psychosis has been grounded in a biomedical framework with the diagnosed individual at the center of intervention and/or research. However, growing evidence reveals the importance of attending to the family and loved ones supporting the individual experiencing psychosis as well as the individual (Onwumere et al., 2019; Reininghaus et al., 2015). Because parents often have a preexisting caregiver role with their children, they are often the first to support their child when they seek treatment (Birchwood & Jackson, 2001; McCann et al., 2011). Family theory offers a relevant theoretical perspective that recognizes the interconnected nature of families wherein the health and well-being of the individual living with psychosis are inextricably linked to that of other family members.

This dissertation provides critical information about the experiences of parents of adults with early psychosis. I investigated predictors of parents' grief through quantitative assessment and explored the nature of parents' grief through in-depth interviewing. In both studies, I applied ambiguous loss theory to the grief experiences of parents of adults with early psychosis. Findings from these studies are two-fold: (a) parents' ambiguity about their child's role and their own role in their child's life is highly interconnected with parents' grief, and (b) parents' experiences of uncertainty require

them to undertake a weighty paradoxical task of navigating their relationship with their child in which they are simultaneously holding on to and letting go of their relationship. An additional finding from this research which supports the need to address the grief in parents of adults with psychosis as well as reflects the need for additional interventions for parents is the post-hoc analysis in Study 1. In this analysis, I found that parents who were experiencing greater levels of grief were also more likely to experience depressive symptoms with a significant positive correlation between parental grief and parental depression (r=.52; p<.001). Findings from Study 2 reinforced this post-hoc finding from Study 1; parents described overwhelming emotions of sadness, guilt, anger, and fear regarding the changes in their child that resulted from the psychosis. Despite the significant correlation between grief and depression in this sample of parents, it appeared that parents who were currently receiving support through group therapy, family therapy, or individual therapy did not experience less depression or grief. This finding supports that parents continue to need interventions to help them cope with the experiences of psychosis in their child. It is important to remember that the parents in this study have been grappling with their child's early psychosis for a relatively short time. The finding that they were still experiencing depression even when receiving support suggests the need for continued support and/or intervention and/or perhaps a different type of support or intervention to help them cope with these experiences. In this chapter, I will elucidate how ambiguous loss concepts can be effectively applied to grief in parents of adult children experiencing early psychosis, and I also point out its limitations.

Boundary Ambiguity

Boundary ambiguity is a foundational concept of ambiguous loss theory (Boss, 1999, 2006, 2016). It is defined as ‘‘a state in which family members are uncertain in their perception about who is in or out of the family and who is performing what roles and

tasks within the family system'' (Carroll et al., 2007, p. 211; Boss & Greenberg, 1984, p. 536). The findings from both studies in this dissertation point to the salience of parents' struggle to navigate their own role in their child's life and to better understand their child's role in the family.

In the first study, there was a high correlation between parental boundary ambiguity and parental grief. Parents who experienced higher levels of grief also experienced greater uncertainty about their own role and their child's role in the family. This is consistent with ambiguous loss theory where researchers have asserted that families experience boundary ambiguity in situations where factors surrounding a loss are unclear and uncertain (Carroll et al., 2007).

In the second study, parents reported their experiences of uncertainty about their child and their struggle to both "hold on to" and simultaneously "let go of" their child, their relationship with their child, and their role in their child's life. The nature of parents' grief was intricately woven into this relational struggle. Although not all parents specifically reflected on their child's psychological absence, numerous parents talked about their struggle to "find" their child following the onset of psychosis by using phrases such as, "Where is my child?" and "I don't know this person." Moreover, many parents reflected on their experience of uncertainty about the child's psychological presence by noting that they were "unsure" of how their child would respond to treatment and the day-to-day unpredictability of their child's behavior.

Physical Presence/Psychological Absence

One of the primary concepts of ambiguous loss theory is that family members experience loss when a family member is either physically absent/psychologically present or physically present/psychologically absent (Boss, 1999, 2006, 2016). As expected, parents reported an experience of grief in Study 1 and Study 2 whereby they indicated an experience of loss in who their child was due to the onset of psychosis.

Although this finding was not surprising based on this particular sample that was specifically recruited to include parents experiencing grief, the phenomenological approach allowed for an in-depth understanding of the nature of their grief based in their lived experiences, and heretofore absent in the literature. Further, the findings from Study 2 added layers of complexity to the application of ambiguous loss theory whereby parents endorsed their experience of their child as physically present, and precariously psychologically present.

The unpredictability associated with the prognosis of psychosis and the fluctuating and uncertain nature of psychosis are not readily captured in the concept of physical presence/psychological absence. Rather, it appears that parents experienced a physical presence of their child while also experiencing a *precarious presence.* Parents did not know when and/or how the psychosis would impact their child's ability to engage in reality. Although precarious presence may be close to what is experienced by families in other situations (e.g., a family member with dementia), the unexpected nature of psychosis combined with the developmental stage of the loved one (late adolescence/early adulthood), and the nature of the parent-child relationship add additional layers of complexity to parents' grief.

Uncertainty and the Myth of Closure

Parents of adults experiencing early psychosis were not able to achieve closure regarding changes in their child, which aptly illustrates what Boss and Carnes (2012) called the "myth of closure" (p. 456). Parents in this study experienced a relationship with their child that is "shrouded in uncertainty" (Boss & Carnes, 2012, p. 456). Parents reflected in both Study 1 (as indicated by the grief measure) and Study 2 that they had lost a sense of who they knew their child to be and struggled to adapt to a new reality and a new relationship with their child. Study 2 confirmed this when parents described the paradoxical phenomenon of both holding on and letting go of their child. Although

some parents found themselves only doing one or the other, either focusing on holding on *or* letting go, most described these encounters simultaneously.

Parents struggled to make decisions in many aspects of their adult child's life after psychosis, but one of the most difficult was deciding where their child would live. This decision also involved the holding on-letting go paradoxical dilemma. One parent was told explicitly by providers that they should allow their child to live with them, while other parents made specific decisions not to allow their child to live with them. Despite their decision, most parents expressed uncertainty and sadness or guilt about specific decisions, and in general, how they had navigated their overall caregiving role with their adult child who was experiencing psychosis.

Contributions of Ambiguous Loss

There are numerous important contributions from ambiguous loss theory that could inform how clinicians provide support for parents responding to psychosis in their adult children. First, is that ambiguous loss theory is not grounded in pathology in an individual or in the family experiencing grief. Given this, it is assumed that there is not a wrong and/or right way of grieving. Rather, grief is understood as a normal response to a complex and uncertain loss. Due to the history of pathologizing grief and of pathologizing parents' responses to their adult children with early psychosis (i.e. expressed emotions), this non-judgmental perspective is a welcome and novel approach to supporting parents which may serve to help them embrace their grief and uncertainty as well as tolerate the complexity of their situation. Second, ambiguous loss theory could be helpful for parents because it provides parents with the language to name their loss (Boss, 2006). Boss (2006) asserted that equipping families with the language of *ambiguous* loss can help families to process their grief and search for meaning. The *naming* of the grief as both a complex and uncertain experience represents a small step that could allow parents to move forward in their lives and relationships with their adult child with early psychosis.

Other concepts which may help families include both/and thinking, revising attachment, and normalizing ambivalence. In “both/and thinking” (Boss, 2021, p. 59) an individual holds two contradictory ideas at the same time without trying to let go of one for the sake of the other. For example, in parents of adults with early psychosis, their child is both physically present and yet precariously absent. From an ambiguous loss perspective, a parent would be encouraged to accept and honor both of these apparently conflicting truths at the same time. Another example of both/and thinking could include parents’ ability to see their need to care for their child *and* to care for their own well-being (Boss, 2021, p. 66). As indicated in this study, parents struggled to balance their own needs as well as that of their own children and they may find it helpful to have both of these needs validated.

Most recently Boss (2021) has identified guidelines for living with loss. Two of these guidelines are revising attachment and normalizing ambivalence. Because parents are faced with an unresolvable dialectic in which their child is both present and precariously absent, their relationship with their child is fundamentally changed. Introducing the idea of revising attachment could provide both words and validation for parents who are learning how to connect and relate to their child in a new way following the onset of psychosis. This therapeutic guideline is consistent with parents’ reports of their struggle to maintain a connection with their child in the midst of the changes brought on by early psychosis. Regarding normalizing ambivalence, Boss (2021) encourages family members that it is understandable and reasonable that they experience conflicting feelings in responding to an ambiguous loss. This is particularly true for parents of adults with early psychosis as they have typically anticipated a decrease in their caregiving role as well as an increase in their independence from their child. However, in early psychosis many of the parents in this research took on additional caregiving and had less independence from their child. Although many

parents were sad about this unexpected change in caregiving, parents also expressed guilt about letting go of their expectations for themselves (e.g., having their child live with them or not having their child live with them). Normalizing ambivalence for parents of adults with early psychosis may provide them with freedom to acknowledge and process their conflicting feelings rather than avoiding them.

Limitations

It is important to note limitations of the two studies in this dissertation that should be taken into consideration when applying research findings to mental health treatment efforts. First, the sample for the quantitative study was small, homogenous (White, mostly mothers), and not representative of the larger population of parents of adults experiencing early psychosis, which limits my ability to generalize the findings to a larger population. It also renders statistical analyses somewhat unstable. Despite Study 1 findings being consistent with past research on parents of adults experiencing SMI (Godress et al., 2005; Stein et al., 2013) and that of caregiver research of adults experiencing early psychosis (Hinojosa-Marques et al., 2019; Patterson et al., 2005), the cross-sectional nature of the study limits my ability to understand parents' experiences over time.

In Study 2, the sample size is comparable to that of other qualitative research and is consistent with guidelines for phenomenological methodology. However, these findings are also limited by the homogeneity of the sample. It is reasonable to expect that parents in this sample, who were recruited from supportive agencies such as NAMI and listservs associated with treatment providers and were different in systematic ways from parents whose children were not seeking treatment. For example, parents who seek out support through NAMI have the time and ability to do so. This may not be the case for many parents who have other caregiving responsibilities or who may not have access to information about supportive resources

Future researchers should seek to recruit a larger and more diverse sample of caregivers, including those who identify as male as well as more racially diverse and larger samples. Families of color are less likely to seek support from the mental system and may rightly have mistrust of mental health providers due to systemic discrimination (Oluwoye et al., 2019). Recruitment of more diverse samples may be more likely if researchers engage in long-term collaboration and work with religious and community organizations where families of color may be more likely to seek support.

Implications for Practice and Research

Parents of adults in late adolescence/early adulthood are typically in a stage of transition; however, parents of adults experiencing early psychosis are navigating a transition imbued with additional and significant complexity. Although parents of young adults without psychosis typically struggle to navigate the launching of their child, parents of adults with early psychosis often see their child have the added struggles of adjusting to a psychiatric diagnosis as well as interacting with a complex and fragmented mental health system. Similarly, parents are learning how psychosis is impacting their child while also understanding how the changes resulting from psychosis are affecting their relationship with their child and their own role in their child's life. Framing these experiences as ambiguous losses may help to normalize grief, to concretize the ubiquitous complexity and uncertainty of their situation and provide them with language to communicate with others in order to gain the acknowledgement and support that is so greatly needed for this difficult journey.

Parents of adults with early psychosis in Study 2 experienced overwhelming emotions (sadness, anger, fear, and guilt) and uncertainty about whether they were over-involved or under-involved in their child's care. Although grief and expressed emotions are not the same experience, research has shown a positive relationship between these constructs (Hinojosa-Marques et al., 2019). Additionally, past research

has demonstrated that family members' expressed emotions towards a loved one experiencing psychosis has negative effects including increased chance in relapses of psychosis as well as increased likelihood of psychiatric hospitalization (O'Driscoll et al., 2019; Koutra et al., 2014). It makes sense that families need spaces in which they can express their complicated emotions, as well as acknowledge the complexity and uncertainty of their situation without disrupting and burdening their child. Unfortunately, opportunities and spaces for parents to voice their grief and expressed emotions are lacking in the current mental health system. Moreover, due to the biomedical paradigm, treatment for mental illness is focused almost solely on the individual with the diagnosis (Price-Robertson et al., 2016). Therefore, opportunities for treatment and intervention center on the individual and typically exclude family members.

Coordinated Specialty Care (CSC) programs such as NAVIGATE provide parents with psychoeducation and peer support (Mueser et al., 2015). However, parents are not eligible for these services if their child does not want them included in their treatment. Parents in this situation are able to seek less formal support through state and national programs such as the National Alliance on Mental Illness (NAMI) family support programs. However, these programs may not be as effective as diagnosis-specific supports offered through programs such as NAVIGATE. Moreover, family support programs available through NAMI are typically available to family members and caregivers whose loved ones are experiencing various mental health diagnoses and are at various stages of their illness. This means that parents of adults experiencing early psychosis may be participating in the same support group as a sibling or spouse of an individual who has been experiencing severe depression or a personality disorder for many years. Family members or caregivers in situations such as these are likely to have some commonality to parents of adults experiencing early psychosis. However, findings from the current study highlight the unique experiences of parents of adults experiencing

early psychosis and point to specific types of support that address the complex and often unpredictable changes in their child.

Providers who serve parents of adults with early psychosis must understand the nature of the mental illness and the unique and precarious role that parents play in the individual's care. Responses used in other situations such as *tough love* may not be helpful. Although some parents in this study indicated that they were encouraged by friends or family to either "kick their child out" or the opposite (have their child live with them), it does not appear that a fixed, one-size-fits-all approach is appropriate. Alternatively, a non-prescriptive response, such as one that is framed by an ambiguous loss perspective wherein a provider or therapist allows the family member to make their own decisions about how to best navigate their relationship with their family member, appears to offer the most promise. Therapists offering support from an ambiguous loss perspective would recognize that situations for parents of adult children with early psychosis are highly subjective and dependent on their family's resources, their child's needs, their relationship with their child, and their own well-being.

Conclusion

Parents who have an adult child experiencing early psychosis are in a liminal space where they are gaining knowledge about changes in their child and speculating how these changes will likely impact their relationship with their child, their role in their child's life, and their child's role in their family. Programs like NAVIGATE can play an essential role in educating and supporting families (Goldstein & Azrin, 2014; Mueser et al., 2015). However, these programs do not adequately address parents' grief or changes in parent's relationship with their child following the onset of psychosis.

Although grief is only one aspect of parents' experiences, the tendency for interventions to pathologize grief, coupled with a lack of support for parents, suggests that it is particularly crucial for an intervention to create space for parents to

acknowledge and experience grief. Interventions that normalize parents' grief responses and allow them to acknowledge their losses and adapt to the changes in their child, their relationship with their child, and their own role as parents, will support parents as they process and make sense of their experiences.

Past research and the dissertation research presented here have shown the interdependent nature of people living with psychosis and their families. We can conclude that programs supporting people living with early psychosis must include interventions for family members. Moreover, future research on this important topic should reflect the salience of parents' roles in adult children's early psychosis experiences for the sake of parents as well as for the individual living with psychosis.

Table 1

Descriptive Statistics of Study Variables

Variable	M	SD
Grief (MIV-TGI)	3.5	.8
Parental relationship quality (PCASS)	38.4	8.4
Boundary ambiguity	2.8	.5
Intolerance of Uncertainty (IUS)	30.3	10

Table 2

Bivariate Correlations among Study Variables

Variable	1	2	3	4
1. Parental Relationship Quality	-			
2. Parental Grief	-.41*	-		
3. Parental Boundary Ambiguity	-.44*	.79**	-	
4. Intolerance of Uncertainty	-.49**	.33	.30	-

Note: *p=<.05; **p=<.01

Table 3

Regression Models Predicting Parental Grief

Variables	Model 1			Model 2			Model 3		
	B [95% CI]	SE B	β	B [95% CI]	SE B	β	B [95% CI]	SE B	β
Parental Relational Quality	-.04 [-.07, -005]	.02	-.41	-.007 [-.03, .02]	.01	-.07	-.03 [-.07, .01]	.02	-.34
Parental Boundary Ambiguity				1.16 [.75,1.57]	.20	.76***			
Intolerance of Uncertainty							.01 [-.02,.04]	.02	.13
Intercept	3.53			3.57			3.53		
N	30			30			30		
F	5.49			22.41			2.9		
Adjusted R^2	.13*			.60***			.12		

Note: *p<.05; **p<.01; ***p<.001

Table 4

Participant Demographic Information for Study 2

Pseudonym	Role	Child Living home?	Years Since Onset	Transcribed
Anne	Mom	Yes	3	Yes
Betty	Mom	No	3	Yes
Cassie	Mom	No	5	No
Dorothy	Mom	Yes	3	Yes
Emma	Mom	No	4	Yes
Francis	Mom	Yes	2	Yes
Gloria	Mom	No	5	Yes
Harriet	Mom	Yes	4	No
Ivan	Father	Yes	2	No
Jessica	Mom	Yes	2	Yes
Kerri	Mom	Yes	3	Yes
Lydia	Mom	No	2	Yes
Molly	Mom	No	4	Yes

Table 5

Parents' Grief Experiences: Study 2

	Domains		
	Adult Child	**Parent's relationship with the Adult Child**	**Parent**
Themes			
Uncertainty	Where is my child? What happened?	What can my child do? What can I expect from my child?	How do I parent?
Overwhelming emotions	Sadness, Guilt, Anger	Sadness, Fear, Guilt	Guilt, Sadness
Paradox of holding on and letting go	A changed child with a changed future and yet still my child	I want to be close to my child, and it's not the same	I am not the same person and I want to be a loving parent

Figure 1

Analytical model 1

Figure 2

Analytical model 2

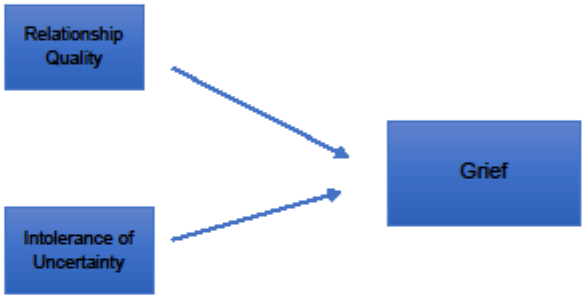
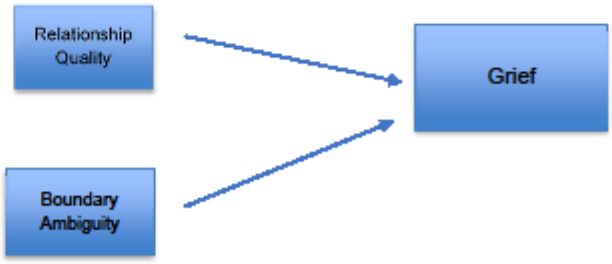


Figure 3

Analytical Model 3



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Appendix A

Demographics:
Age (years), Gender (male/female/nonbinary), Partner Status (Single/Partnered/Married/Divorced/Widowed), Race/Ethnicity (Select all that apply: Black or African American, Hispanic or Latino; White, American Indian or Alaska Native, Asian, and Native Hawaiian or Other Pacific Islander), Country of origin (open entry), Age of child (number in years), Gender of the child (male/female/non-binary), Time since first treatment (number in months/years), Time since psychosis diagnosis (number in months/years), First treatment setting (hospital, outpatient clinic (therapist/counselor/psychiatrist), emergency room, jail, school), Number of hospitalizations since onset of psychosis (number), Number of hospitalizations in the last year (number), Engagement in treatment (checkbox check all that apply: individual therapy, group therapy, day treatment, partial hospitalization, case management, medications), Has your child been civilly committed due to their mental illness? Has your child been incarcerated for behavior related to their mental illness? Caregiver status ("Do you consider yourself a caregiver of your child?"); Caregiver role ("Do you consider yourself a caregiver to any others in your family? If so, how many other people?), Socioeconomic status (average household monthly income (0-$1,000, Over a $1,000 and less than 2,000, Over 2,000 and less than 3,000, Over 3,000 less than 4,000, Over $4,000 and less than 5,000; Over 5,000 and less than 6,000, Over $6000 and less than $7,000; Over 7,000 and less than $8,000; Over 8,000 less $9,000; Over $9,000) Employment status- select all that apply (Unemployed, Part-time, Full-time; Student; Retired)

Parent Child Affectional Solidarity Scale (Silverstein & Bengtson, 1991). A similar scale has been used to measure relationship quality between parents and adult children with schizophrenia (Greenberg et al., 2004).
Rate each statement on the 6-point Likert Scale: 1-6
1= not much at all, 2 =not much, 3= some, 4 =pretty much, 5 =very much, 6 =extremely much
PCASS_1. How well do you feel your child understands you?
PCASS_2. How well do you feel your child trusts you?
PCASS_3. How fair do you feel your child is toward you?
PCASS_4. How much respect do you feel from this child?
PCASS_5. How much affection do you feel your child has for you?
PCASS_6. How well do you feel you understand him or her?
PCASS_7. How well do you trust your child?
PCASS_8. How fair do you feel you are toward your child?
PCASS_9. How much do you respect your child?
PCASS_10. How much affection do you have towards your child?

Mental Illness Version of the Texas Inventory of Grief (MIV-TIG) (Miller et al., 1990)
Instructions: Rate the following items on a scale of 1-5
1=Completely False, 2= Mostly False, 3= Both False and True, 4=Mostly True, 5= Completely True
(At child's diagnosis)
TGI_1 I found it hard to get along with certain people.
TGI_2 I found it hard to work well when I became aware of his/her mental illness.

TGI_3 I lost interest in other family members, friends, and relatives.
TGI_4 I found a need to do things the way he/she used to do them.
TGI_5 I was unusually irritable.
TGI_6 I couldn't keep up with my usual activities for the first three months.
TGI_7 I was angry with him/her for the changes that were taking place.
TGI_8 I found it hard to sleep.

(Presently)
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TGI_9. I cry when I think about how he/she used to be before the illness.
TGI_10. I cry when I think about how he/she could have been if not for the illness.
TGI_11. I get upset when I think about how he/she used to be before the illness.
TGI_12. I get upset when I think about how he/she could have been if not for the illness.

TGI_13. I very much miss the way he/she used to be.
TGI_14. It is painful to recall memories of how he/she used to be.
TGI_15. I am preoccupied with thoughts about how he/she used to be before the illness.
TGI_16. I am preoccupied with thoughts about how he/she could have been if not for the illness.
TGI_17. I hide tears when I think about them.
TGI_18. No one will ever take the place that he/she used to have in my life.
TGI_19. I can't avoid thinking about how he/she was before the illness.
TGI_20. I can't avoid thinking about how he/she could have been if not for the illness.
TGI_21. I feel it is unfair that he/she became mentally ill.
TGI_22. Things and people around me still remind me of the he/she used to be.
TGI_23. I cannot accept his/her mental illness.
TGI_24. At times I still feel the need to cry for him/her.

Please think back to when his/her first serious problems began.
Please rate the intensity of your grief for each of the following time periods after realizing that your child was ill. Use a scale of 1 (no or low grief) to 5 (very intense grief) to rate each time period.
TGI_25Time periods 0 to 1 year:
TGI_26More than one year but less than 3 years:
TGI_27More than 3 years but less than 5 years:

Boundary Ambiguity Measure (Boss et al., 1990)

The following statements are about your relationship with your child with psychosis (As you read, imagine their name in the blank space in each sentence.) Using the scale provided as a guideline, click the number that best shows how you feel and place it in the blank to the left of each item. There are no right or wrong answers. Please answer every question even if you are unsure.

Instructions: 5-point Likert scale (Total score averaged excluding “unsure items”)

1=Strongly Disagree, 2=Disagree, 3=Agree 4=Strongly Agree 5=unsure

BAM_1 I feel guilty when I get out of the house to do something enjoyable while ____ remains at home.

BAM_2 I feel it will be difficult if not impossible to carve out my own life as _____needs my help.
BAM_3 I feel incapable of establishing friendships right now.
BAM_4 I feel I cannot go anywhere without first thinking about _____ and their needs.
BAM_5 I feel like I have no time for myself.
BAM_6 Sometimes I am not sure where _____ fits in as part of the family.
BAM_7 I'm not sure what I should expect _____ to do.
BAM_8 I often feel mixed up about how much I should be doing for_____.
BAM_9 I put _____ needs before my own.
BAM_10 My family and I often have disagreements about my involvement with _____.
BAM_11When I'm not with _____I find myself wondering how they are getting along.
BAM_12 Family members tend to ignore_____.
BAM_13_____no longer feels like my child.
BAM_14 I think about _____ a lot.

Intolerance of Uncertainty Scale (Carleton et al., 2007) IUS

Please indicate the number that best corresponds to how much you agree with each of the following items:

1=Not at all characteristic, 2=A little characteristic of me; 3=Somewhat characteristic of me; 4=Very characteristic of me; 5=Entirely characteristic of me

Prospective

IUS_1 Unforeseen events upset me greatly.
IUS_2 It upsets me not having all the information I need.
IUS_3 One should always look ahead so as to avoid surprises.
IUS_4 A small, unforeseen event can spoil everything, even with the best of planning.
IUS_5I always want to know what the future has in store for me.
IUS_6I can't stand being taken by surprise.
IUS_7I should be able to organize everything in advance.

Inhibitory

IUS_8Uncertainty keeps me from living a full life.
IUS_9When it's time to act, anxiety paralyzes me.
IUS_10When I'm uncertain, I can't function very well.
IUS_11The smallest doubt can't stop me from acting.
IUS_12 I must get away from all uncertain situations.

Center for Epidemiologic Studies: Depression scale (CES-D)-10 (Andreson et al., 2013)

During the past week . . .

Rate on a Likert-scale: Rarely or None of the Time (Less than 1 Day); 1 Some or a Little of the Time (1–2 Days); 2 Occasionally or a Moderate Amount of Time (3–4 Days); 3 Most or All of the Time (5–7 Days)

CESD_1 I was bothered by things that usually don't bother me.
CESD_2 I had trouble keeping my mind on what I was doing.
CESD_3 I felt depressed.
CESD_4. I felt that everything I did was an effort.
CESD_5. I felt hopeful about the future.
CESD_6. I felt fearful.
CESD_7. My sleep was restless.
CESD_8. I was happy.

Appendix B

Interview Questions

1. Can you tell me about yourself?
2. Can you tell me about your child?
3. How did you first know your child was ill? Describe this experience.
4. Describe what your life has been like for you since your child became ill.
5. Describe what your relationship has been like with your child since they became ill?
6. Have you noticed changes in your relationship? If so, what?
7. Have you noticed changes in yourself since your child became ill? If so, what?
8. What thoughts come to mind as we talk about your child's illness?
9. What feelings come to mind as we talk about your child's illness?
10. What advice would you give to parents who have a child with this illness?
11. Is there anything else you would like me to know about you or your child or this experience?

Prompting questions

1. What are some examples?
2. Can you describe more of what you mean by . . . ?

Appendix C

Full Positionality Statement

In reflecting on my personal and professional identity, I recognize that I bring both privileges and a unique perspective(s) to my field of study. I believe that by reflecting on these, I will better position myself to engage in and conduct my research. I am a White cisgender woman, and I am married to a White cisgender male who is employed full-time. We have two children. I am privileged to have a home and access to resources such as healthcare through my spouses' work. Our current economic status is middle class. However, as a first-generation college graduate and (now) graduate student from a lower-class socioeconomic background, I have often struggled to understand the culture of academia. This cultural gap has made it difficult to communicate with my family and community about my choices to pursue academia. Nonetheless, my race, education, and socioeconomic resources afford me tremendous privilege in this time of considerable racial and financial inequity.

I earned my MA in counseling psychology in 2000, and I worked for over 13 years in the field of mental health. The time away from academia impacts how I view my role as a researcher, and it is from this work experience that my interest in early psychosis arose. I worked for approximately three years in residential treatment with individuals experiencing serious and persistent mental illness (SPMI). Many of the individuals living in the treatment center were transitioning from state psychiatric hospitals or acute care hospitals to more independent living. I often communicated and interacted with families (mostly parents) about their child's condition. In this setting, we were often able to obtain releases of information to talk with family due to clients living within the treatments setting. However, I also worked for nine years in a crisis outreach team where I often received calls from family (many parents) who were concerned about

their newly diagnosed adult child. In many of these situations I was faced with confidentiality restrictions where I was unable to disclose information to parents about their child or their treatment. Because the mental health system is grounded in caring for individuals rather than families, I found that treatment often excludes the involvement of family.