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Parents' Grief in the Context of Adult Child Mental Illness: A Qualitative Review

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Abstract Research indicates that parents and other family members often grieve their child or relative's mental illness. This grief appears resultant from a profound sense of loss, which has been described as complicated and nonfinite (e.g., Atkinson in Am J Psychiatry 151(8):1137–1139, 1994; Davis and Schultz in Soc Sci Med 46(3):369–379, 1998; Jones in Br J Soc Work 34:961–979, 2004; MacGregor in Soc Work 39(2):160–166, 1994; Osborne and Coyle in Couns Psychol Q 15(4):307–323, 2002; Ozgul in Aust N Z J Fam Ther 25(4):183–187, 2004; Tuck et al. in Arch Psychiatric Nurs 11(3):118–125, 1997). This paper reviews existent research in this emerging field, with a focus on parents' grief experience in relation to their adult child's mental disorder. Studies that explore parents' and family members' grief, using both qualitative and quantitative methodologies, are considered. Research evidence for the association between parents' and family members' grief and other outcomes are discussed. Findings concerning the prediction of grief in parents and family members who have a child or relative with a mental disorder will be reviewed. Finally, this paper considers methodological and theoretical issues associated with existent research and presents options for further study.

Keywords Mental illness · Grief · Loss · Families · Children

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Introduction

One outcome of the deinstitutionalization movement was increased responsibility of the family in managing their relative's mental disorder (Baronet 1999; McCausland 1987). A perhaps less anticipated consequence of this reform was the distress experienced by family members as they assumed this caregiving role (e.g., Doll 1976; Gubman and Tessler 1987). Since the mid-1950s and 1960s, a vast number of studies have sought to capture the impact of mental illness on the family (e.g., Clausen and Yarrow 1955; Grad and Sainsbury 1968; Hatfield 1978; Lefley 1996; Noh and Turner 1987; Sveinbjarnardottir and de Casterli 1997; Thompson and Doll 1982). Much of the research concerning families' experience of their loved one's mental disorder has focused on the many burdens, both objective and subjective, with which parents, siblings, spouses, children and other family members of a mentally ill relative are faced (e.g., Hatfield 1978; Lefley 1996; Maurin and Boyd 1990; Rose 1996; Solomon and Draine 1995; Thompson and Doll 1982). Indeed, families are often encumbered with problems associated with their relative's illness; such as, coping with symptoms of the disorder (e.g., positive and negative symptomatology, mood disturbance, disruptive, socially inappropriate or potentially harmful behaviors), increased caregiving responsibilities, disruptions to family life (e.g., financial hardships, strained relationships, employment difficulties, compromised social life, impaired physical and psychological well-being), adjusting to shortcomings of the mental health system and coping with oppressive social stigma surrounding mental illness (Baronet 1999; Grad and Sainsbury 1968; Gubman and Tessler 1987; Hatfield 1978; Lefley 1996; Maurin and Boyd 1990; Noh and Avison 1988; Young et al. 2004). In addition to these hardships, families often experience

marked personal suffering in relation to their relative's condition, which is often characterized by stress, exhaustion, worry, sadness and strain (Lefley 1996; Maurin and Boyd 1990; Montgomery et al. 1985; Reinhard and Horwitz 1995; Young et al. 2004).

Olshanksy (1962) was the first to explicitly propose that parents' experience of their child's mental illness may include pervasive and recurrent sadness, which he labeled chronic sorrow. Based on the observations of parents who had a child with mental retardation, Olshanksy (1962) reported that parents feel acute loss in reaction to their child's condition. Olshanksy (1962) perceived this loss as complex and ongoing; unlike loss incurred through bereavement, this loss was described as having no predictable end and possibly involved many losses, both real and symbolic. Chronic sorrow was perceived as a normal parental response to the complex loss associated with their child's mental retardation (Olshanksy 1962). Twenty years after Olshanksy's (1962) comments, a number of studies have emerged documenting the incidence of this phenomenon in parents of children with various mental and physical conditions; including, chronic mental illness (e.g., Eakes 1995; Howard 1998), mental retardation (e.g., Wikler et al. 1981), Down syndrome (e.g., Damrosch and Perry 1989), sickle cell disease (e.g., Northington 2000), lissencephaly (e.g., Scornaienchi 2003) and children born premature (e.g., Fraley 1986).

Although the grief literature is recognized for its theoretical discordance (Bonanno and Kaltman 2001), there is a general consensus that grief is the psychological response to bereavement or another loss experience (Centre for the Advancement of Health 2004). Grief has been conceptualized in accordance with various theoretical perspectives; for example, Freud (1953) and Lindemann (1944) proposed that grief is a task that involves confronting the reality of the loss and severing emotional ties to the deceased (see also Rothaupt and Becker 2007). Bowlby (e.g., Bowlby 1980; Bowlby and Parkes 1970) suggested grief is a form of separation anxiety, and that mourners proceed through grief phases—bluntness, yearning, despair and disorganization, and reorganization—with the aim of restoring proximity to the attachment figure (see also Davies 2004; Parkes 2001). Kübler-Ross' (1969) stages of dying have been applied, somewhat controversially, to individuals' grief reaction, while Worden (1982, 1996) argued that individuals proceeded through grief tasks; including accepting the loss, working through the pain, adjusting to an environment in which the deceased is absent, and moving on with life.

Early grief models have been subject to criticism (Gluhoski 1995). More recently, contemporary theoretical frameworks have been used to explain the grieving process. Neimeyer et al. (e.g., Neimeyer 2000; Neimeyer et al. 2001) propose that grief is related to difficulties integrating a loss into personal systems of meaning. The dual process model of coping (e.g., Stroebe and Schut 1999) stipulates that the grieving individual adapts to loss by vacillating between loss-oriented (attempts to resolve the loss) and restoration-orientation (attempts to adapt to changes in circumstances and difficulties resulting from the loss) coping (see also Centre for the Advancement of Health 2004). Folkman's (2001) cognitive stress theory—of particular relevance is the role of positive emotions for adaptive grieving—has been used to conceptualize grieving, as has Horowitz's (e.g., 1986) stress response syndrome. Horowitz (1986) identified two main components of coping with trauma; a sense of reliving emotions and ideas pertaining to the event (Intrusion) and denial (Avoidance), which may be evidenced by, for example, amnesia about the event or difficulties visualizing event-specific memories (Horowitz 1986; Stroebe and Schut 1999). Some have conceptualized bereavement as an event to which individuals respond via these cognitive processes (e.g., Dyregrov and Matthiesen 1987; Horowitz et al. 1981). More general cognitive–behavioral perspectives have also been applied to the grief experience (e.g., Boelen et al. 2006; Gluhoski 1995; Malkinson 2001). Irrespective of its theoretical stance, grief research is typically orientated around separating normal from pathological grief, identifying determinants of individual variability in grieving, identifying grief outcomes, and examining the efficacy and effectiveness of grief interventions (Bonanno and Kaltman 1999; Centre for the Advancement of Health 2004).

It has recently been acknowledged that parents' and other family members' experience of their adult child or relative's mental disorder may also involve strong feelings of grief. Commentaries by health professionals and consumers (e.g., Ellis 1989; MacGregor 1994; McElroy 1987; Parker 1993; Wasow 1995; Young et al. 2004) suggest that parents' grief may be associated with a profound sense of loss; loss of their premorbid, healthier child, loss of hopes and dreams for their child's future, loss of former familial relationships, loss of perceived parental competence and loss of security and certainty. Some have suggested that such grief does not abate over time; rather, it intensifies and remits as parents are continuously confronted by reminders of the discrepancy between what they hoped their child would be and what their child has become (Davis and Schultz 1998; Parker 1993). Indeed, McElroy (1987) commented on the dynamics of parents' and families' grieving process:

> Tremendous psychological loss and grief are experienced by families of the seriously mentally ill. The cyclical nature of some of the psychiatric illnesses

> and the periodic reappearance of the "former self" creates prolonged periods of grieving…families of the mentally ill cope with this unsanctioned form of grief daily (p. 228)

Consistent with these observations, there has been a steady emergence of studies examining parents' and families' grief in response to the loss of a child or relative to mental illness.

This paper critically reviews existent research on parental and familial grief in response to an adult child or other relative's mental disorder. Studies seeking to describe parents' and families' grief and loss, using qualitative and quantitative methodologies, will be considered. Findings pertaining to variables associated with grief will be discussed. This paper will also review studies investigating the prediction of grief in parents and other family members who have an adult child or relative with a mental disorder. Theoretical and methodological issues in this line of research will be considered, followed by a discussion of avenues for further study.

Method

Inclusion Criteria

Studies were identified through a computer search of the PsychINFO database (1840–current). Studies were selected if their title included *parent* or *families* or *parental* and *grief* or *grieving* or *loss* or *sorrow* or *bereavement* or *bereaved* and *mental illness* or *mentally ill* or *mental disorder* or *mental disability* and *child* or *adolescent* or *children*. The references of each article were examined to ensure relevant papers were not overlooked. Papers were included if they were peer reviewed and examined grief, loss or chronic sorrow in parents of a child with a diagnosed mental disorder. In three identified studies (Jones 2004; Miller et al. 1990; Solomon and Draine 1996), a proportion of other family members (e.g., siblings, children and spouses) were included in parent samples. The focus of this review is the grief and loss experienced by parents in response to their adult child's disorder. However, given the majority of participants in these mixed samples were parents—approximately 76% of Solomon and Draine's (1996) sample were parents and Jones (2004) recruited 23 mothers and fathers and 16 siblings—these three studies were included. Twelve studies met criteria and were selected for review.

Study Characteristics

The reviewed studies had samples that ranged from four to 225 participants. Three studies restricted their sample to parent dyads, while the remaining studies did not necessarily require both parents' participation. Of the twelve studies, seven adopted a qualitative approach. Two qualitative studies conducted parent focus groups; these occurred once or weekly over the course of 1 month. The remaining qualitative studies used loosely structured interviews to collected data. Five studies adopted quantitative methodologies.

Five studies limited their sample to parents of adult children with Schizophrenia. One study extended this criterion to include parents of adult children with Schizophrenia or Schizoaffective disorder. Three studies recruited parents or family members of an adult child or relative who had received a diagnosis of Schizophrenia or Bipolar disorder. Three studies targeted a somewhat broader range of mental disorders; samples included parents or family members of an adult child or relative who had Schizophrenia, Bipolar disorder, major affective disorder or a nonspecified mental illness diagnosis.

Sample Characteristics

Based on available demographic data—sample characteristics were insufficiently described in some studies—participants were predominantly female (60%) and averaged 62 years of age. Respondents were mostly Caucasian and of middle socioeconomic status. One study reported that more than half (54%) their sample held a college degree. Respondents were typically parents (89%), the majority of whom were mothers. The individual with a mental illness was typically male and averaged 33 years of age. The vast majority of individuals had received a diagnosis of Schizophrenia or less commonly, Bipolar disorder. Duration of mental illness ranged from less than 12 months to more than 20 years. Of the studies that provided these data, the proportion of respondents who resided with their ill relative ranged from 17 to 100%. Participants were recruited via support organizations, community advertising, and inpatient and outpatient settings. In summary, the vast majority of research examining loss and grief in response to a child's mental illness has been conducted with aging parents who have an adult child, often male, with a diagnosis of Schizophrenia.

Results

Studies collectively document four types of findings. First, qualitative analyses describe parents' and other family members' loss and grief experience, including the phenomenon of chronic sorrow. Second, descriptive statistics document the occurrence of grief in parents and other family members who have a child or relative with a mental disorder. Third, correlation analyses depict the association

between grief and various outcomes. Lastly, correlation statistics identify factors that are predictive of parents' and families' grieving experience. Table 1 summarizes the sampling, design, method and major findings of the reviewed studies.

Phenomenology of Loss and Grief: Qualitative Findings

Nine studies adopted qualitative methods to chronicle parents' and other family members' loss and grief experience. Similar themes emerged from this research. Parents reflected on their realization that something may be wrong with their child (Mohr and Regan-Kubinski 2001; Ozgul 2004; Tuck et al. 1997). This process of awareness often involved questioning, realization and a sense of imminent crisis (Mohr and Regan-Kubinski 2001). Mohr and Regan-Kubinski (2001) conducted a series of focus groups with four parent dyads whose child (aged between 17 and 31 years) was diagnosed with Schizophrenia or a major affective disorder that required hospitalization. To illustrate parents' initial questioning of their child's behavior, the researchers shared an excerpt from a mother whose daughter developed difficulties 7 years ago:

> Mom: She said "I just want to die. I just want to die." And that was a red flag for me. I was like, "This isn't typical for (child), you know, a 10-year-old to be wanting to die? What's going on?" (Mohr and Regan-Kubinski 2001, p. 72)

Ozgul (2004) conducted a focus group with 22 mothers and fathers who had an adult child with Schizophrenia. Parents in this study reported a similar experience. Participants sensed something was wrong with their child, which led to feelings of fear, confusion and apprehension (Ozgul 2004). One parent commented "something was happening but I could not put my finger on it…I didn't know what I had to do…" (Ozgul 2004, p. 184). Tuck et al. (1997) reported that nine parents who had an adult son with Schizophrenia or Schizoaffective disorder experienced a similar process of realization.

Parents' decision to act was often precipitated by attempts to rationalize or make sense of their circumstances (Mohr and Regan-Kubinski 2001; Tuck et al. 1997). Excusing their child's behavior—or attributing the situation to their own deficiencies as a parent—was common (Mohr and Regan-Kubinski 2001; Osborne and Coyle 2002; Tuck et al. 1997). Indeed, participants in Tuck et al.'s (1997) research recalled initially perceiving their child's atypical or disturbing behaviors as normal, as illustrated by the comment "it was like he liked to do everything that was repetitive, which most children do, which isn't abnormal, okay, it's not abnormal, I know that, see" (Tuck et al. 1997, p. 120). Osborne and Coyle (2002) interviewed four parents of an adult child with Schizophrenia; consistent with other studies, one mother attributed her son's pathological behaviors to situational factors rather than manifestation of a mental illness. Moreover, this parent directly acknowledged disregarding her son's unusual behaviors as a means to safeguard herself from admitting her child had a mental disorder (Osborne and Coyle 2002).

Research suggests that compensatory attempts often failed, and parents sensed impending crisis (Mohr and Regan-Kubinski 2001). Some parents reported a climactic moment of insight that prompted immediate action:

> Mom: It was pitiful. Oh Lord! I had to call an ambulance…I mean she was just goin' off….She's standing in front of the mirror just scratching her face, scratching her face—how much she doesn't like the freckles on her face, she didn't like the way she looked, and she started lookin' strange, and all of a sudden she just started screaming and hollerin'—hollerin' this holler that I never heard before. And I had to lay on her and hold her down, and she was kicking and screaming—and they came and took her. My God, they took her and I let 'em (Mohr and Regan-Kubinski 2001, p. 73).

For others parents, taking action occurred more gradually. One mother in Mohr and Regan-Kubinski's (2001) research sought to validate her concerns about her daughter by tentatively seeking a friend's advice. Most parents sought professional opinion. Participants in Tuck et al.'s (1997) study consulted school counselors, family doctors, psychiatrists and therapists to seek an explanation and assistance for their sons' behavior. Ozgul (2004) and Mohr and Regan-Kubinski (2001) also described parents' help seeking experience. Confusing or noncommittal advice, practitioners' apparent reluctance to give their child a definitive diagnosis, as well as excessive paperwork and financial expenses incurred through service engagement contributed to parents feeling overwhelmed, frustrated, alienated, confused and powerless (Ozgul 2004; Tuck et al. 1997).

The reviewed studies chronicle parents' experience of witnessing their child's "descent into mental illness" (Mohr and Regan-Kubinski 2001, p. 73; Osborne and Coyle 2002). Several participants elaborated on their emotional collapse, which often involved anxiety, crying, exhaustion and panic. A mother and father's anguish at having to leave their daughter at hospital was captured by Mohr and Regan-Kubinski (2001):

> Mom: I remember—I remember walking down the hall and having to leave her standing there. And we got into the parking lot, and we cried and prayed, prayed together in the car…

Table 1 Study design, method and primary findings

Source	Sample	Design and method	Major findings
Atkinson (1994)	3 × Parent dyad groups: parents of child with Schizophrenia, parents whose child died, parents of child with organic personality disorder	Cross-sectional, quantitative, $N = 150$. Intake and measures; Beck Depression Inventory (BDI; Beck and Steer 1987), Hamilton Anxiety Rating Scale (Hamilton 1959), Michigan Drug and Alcohol Screening Test (Moore 1972), Mental Illness Version of the Texas Inventory of Grief (MIV-TIG; Miller et al. 1990)/Texas Inventory of Grief (TIG; Faschingbauer et al. 1977). ANOVAs and follow-ups (Scheffé and Newman-Keuls) to determine group differences on continuous variables (IVs)	Parents of child with Schizophrenia reported significantly less grief. Parents of child with Schizophrenia reported more current grief compared to initial grief. Parents in other groups reported significant decrease from initial to current grief
Davis and Schultz (1998)	Parent dyads who had adult child with Schizophrenia	Cross-sectional, quantitative, $N = 32$, 16 parent dyads. Participants completed background survey, Impact of Events Scale (IES; Horowitz et al. 1979), Experience of Stress Scale (ESS; developer not specified), Schedule of Recent Events (Holmes and Rahe 1967), unpublished parental distress measure. ANOVAs and correlations to investigate if grief is influenced by parents' gender/contact with child	Dyads grieved child's disorder. No significant effect of gender on grief. Contact hours with child did not significantly influence mothers' and fathers' grief, with the exception of intrusive thoughts
Eakes (1995)	Parent dyads and mothers of male child with Schizophrenia or Bipolar disorder	Cross-sectional, qualitative, $N = 10$. Participants administered Burke/NCRS Chronic Sorrow Questionnaire (Burke et al. 1992)	Eight parents experienced chronic sorrow. Anger, frustration and confusion evident. Caregiving elicited chronic sorrow
Godress et al. (2005)	Parents of adult with Schizophrenia or other mental illness	Cross-sectional, quantitative, $N = 71$. Parents completed IES (Horowitz et al. 1979), MIV-TIG (Miller et al. 1990), MOS SF-36 Health Survey (Ware 2001), modified Attachment Style Measure (Simpson 1990), unpublished parent–child affective experiences scale. Correlations to examine relationship between grief and (a) parents' physical/mental health status (b) parent–child attachment (c) parent–child affective relationship. Parents divided into five cohorts based on years elapsed since diagnosis; ANOVAs to examine time since diagnosis on grief	Participants reported current grief. Parents one year postdiagnosis had significantly higher IES Intrusion scores than parents in cohort where more than 10 years had elapsed. MIV-TIG scores significantly higher for parents in the one year/four to five year postdiagnosis cohorts than parents more than 10 years post. Greater grief correlated with low physical/mental health status, anxious/ambivalent parent–child attachment, negative-affective parent–child relationship
Jones (2002)	Parents/siblings of adult with Schizophrenia or Bipolar disorder	Cross-sectional, qualitative, $N = 49$. Comprehensive, unstructured interviews	Three factors that complicated interviewee's loss: fear of betrayal, anger and shame
Miller et al. (1990)	Family members of adult with Schizophrenia or Bipolar disorder	Cross-sectional, quantitative, $N = 58$. Participants given unpublished demographic questionnaire and MIV-TIG (Miller et al. 1990). Correlation analyses to examine association between grief and other variables	Participants reported low initial and high current grief. Nonsignificant/weak correlations between current grief and mental illness type, participant's relation to the individual, whether participant resided with relative, hospitalization history, age of illness onset, illness duration, strength of participant–relative relationship, participant's caregiving duties
Mohr and Regan-Kubinski (2001)	Parent dyads of child with mental illness	Cross-sectional, qualitative, $N = 8$. Participated in four weekly focus groups	Key themes identified: early nightmares, action, overwhelmed, fear, anguish, guilt and sequelae

Table 1 continued

Source	Sample	Design and method	Major findings
Osborne and Coyle (2002)	Parents of adult child with Schizophrenia	Cross-sectional, qualitative. $N = 4$. Participants interviewed	Three parents reported loss in response to child's diagnosis. One participant sensed losing daughter's former self
Ozgul (2004)	Parents who had adult child with Schizophrenia	Cross-sectional, qualitative, $N = 22$. Focus group	Participants grieved losses incurred as function of child's disorder. Grief nonlinear, complicated and protracted
Solomon and Draine (1996)	Family members who had responsibility for an adult relative with Schizophrenia or major affective disorder	Cross-sectional, quantitative, $N = 225$. Participants given interview; included, demographics, illness history, history of participant–relative relationship, MIV-TIG (Miller et al. 1990), measure of relative's functioning, adapted burden interview (Pai and Kapur 1981), Norbeck Social Support Questionnaire (Norbeck et al. 1981). Hierarchical multiple regression to examine contribution of IVs for families' grief	High grief significantly correlated with being white, less education, having relative who has been mentally ill fewer years, owning smaller social network, receiving more emotional support, being in crisis, not having ill relative reside with the respondent, greater subjective burden
Tuck et al. (1997)	Primary caregiver parents of adult child with Schizophrenia/ schizoaffective disorder	Cross-sectional, qualitative, $N = 9$. Parents individually interviewed	Themes: struggling to reframe events as normal, seeking help, transformation of loved child, living with shifting levels of hope, endless caring, gathering meaning, self-preservation
Wiens and Daniluk (2009)	Fathers of adult child with Schizophrenia	Cross-sectional, qualitative, $N = 6$. Interviews	Themes: reflection on roles and responsibilities, perceived devastation and vulnerability, sadness and loss, frustration with the mental health system, sense of admiration for their child, personal growth and learning

> Dad: Toughest thing we've ever had to do. The toughest thing.
> Mom: Well, (Dad) is usually not real—well, I don't want to say he's not emotional, because he has very deep feelings. He doesn't usually cry. But he—he has cried. I mean, he's not—and he's not ashamed of that. But he's—that night, he bawled, just bawled in the car.
> Dad: Like ripping out a part of your life, and your body, your heart and just leaving it, you know? Walking away from it (Mohr and Regan-Kubinski 2001, p. 74).

Some parents recalled feeling relief and hope when they first learnt their child had a mental illness (Ozgul 2004; Tuck et al. 1997). To receive a diagnosis confirmed parents' intuitions about their child, ended their prolonged quest for answers and disproved fears that they had caused their child's behavior (Ozgul 2004; Tuck et al. 1997).

However, parents' relief was often short lived. Ozgul (2004) and others (e.g., Tuck et al. 1997; Wiens and Daniluk 2009) found participants soon started grieving as the magnitude of their loss became apparent. For some parents, grief was an acute and immediate response. For one participant in Wiens and Daniluk's (2009) study of six fathers' experience of their adult child's Schizophrenia, hearing his daughter's diagnosis triggered a profound grief response:

> When he said that our daughter has schizophrenia, I just felt like the bottom had fallen out of my world and I felt very sad for my daughter. I felt like it was a death sentence for her and I was mute (p. 343).

Observations by Osborne and Coyle (2002), Wiens and Daniluk (2009) and Ozgul (2004) suggest parents' grief stemmed from the myriad of losses they incurred; including, loss of who their child once was, loss of their child's potential, loss of hopes and dreams for their child's future and losses incurred in family dynamics and relationships (Ozgul 2004; Wiens and Daniluk 2009). This sentiment was echoed by a father in Wiens and Daniluk's (2009) research, who reflected that "this was a huge loss. The death of my father, the death of my mother, other deaths I've experienced—I've never felt like I did when my child was diagnosed with schizophrenia" (p. 344). Another father made a similar comment:

> I really did feel he was going to make a mark in the world. I realize now that that's not going to happen. I can see that the illness has really taken away a lot of that potential… So that image, the image of him being successful—of having a great life, is gone (Wiens and Daniluk 2009, p. 343).

Comparable parental observations were noted by Tuck et al. (1997):

> He's not a person, he's not the same, all my hopes for him were gone, he would never drive a car, date, get a job, go to school. He doesn't communicate. Perhaps all the things I wanted for him earlier died. This son (pause) this person (pause) now all we can do is work with what we've got (p. 121).

Jones (2004) interviewed parents and siblings of an adult with Schizophrenia or Bipolar disorder to explore the complexity of their loss experience. He identified three factors that complicate family members' loss. First, parents and siblings often perceived their relative as a different person after the illness developed. Jones (2004) reported that respondents experienced this personality change as a significant loss. Despite feeling they had lost the child or sibling they once knew, their loved one was still present, though perhaps altered (Jones 2004). Jones (2004) found that parents and siblings were often reminded of what their loved one was like before the illness, and compared this lost person to the person physically present.

Jones (2004) further discovered that anger also complicated families' loss experience. Some parents and siblings reported harboring anger toward their mentally ill relative (Jones 2004). For some respondents, the loss surrounding their relative's illness was also complicated by hidden shame (Jones 2004). It was suggested that shame may stem from stigma surrounding mental illness and the threat of the relative's diagnosis to the family member's own identity and status (Jones 2004).

According to Jones (2004), the complex and nonfinite nature of this loss makes grieving difficult. Despite the continued presence of their child or sibling, participants had to essentially relinquish memories of how their relative used to be (Jones 2004). This may be challenging, however, if family members witness periodic glimpses of their relative's former self (Osborne and Coyle 2002). One mother in Osborne and Coyle's (2002) study explained how her son's premorbid self was trapped, because there were times when he would "laugh and carry on just like he used to" (p. 311). This participant described the reemergence of her son's former self like "a blinding glimpse of life…you think [sigh] 'that's the person we used to know and love'" (Osborne and Coyle 2002, p. 311). These qualitative findings suggest parents' and other family members' grief does not necessarily abate over time (Osborne and Coyle 2002; Ozgul 2004). Parents' grief appears to increase and decrease. Reminders of their loss—cues may include special events, milestones, relapses or disruptions to family life, for instance—have been reported to trigger grieving (Ozgul 2004).

The notion that a child or relative's mental disorder is a complex, unending loss that parents and families continue to grieve adheres to Olshanksy's (1962) concept of chronic sorrow (Eakes 1995). Eakes (1995) identified chronic sorrow in eight out of ten parents who had an adult child with Schizophrenia or Bipolar disorder. Consistent with Ozgul's (2004) observations, Eakes (1995) reported that participants' chronic sorrow was continuously evoked by several factors. For most parents, ongoing caregiving duties were frequent precipitants (Eakes 1995). This father's response illustrates the pervasive nature of his sorrow and is comparable to parents' grief reported in other studies (e.g., Mohr and Regan-Kubinski 2001; Ozgul 2004; Tuck et al. 1997; Wiens and Daniluk 2009):

> …grief is an emotion that abates but does not die. The grief has abated somewhat, but certainly doesn't leave. When the phone rings at night, maybe he's in the hospital. It's still a fear and it will be for as long as I live. The grief isn't on the surface, but it's there (Eakes 1995, p. 79).

To summarize findings from these qualitative investigations, parents and family members often reported that learning their child or relative had a mental illness was an intensely emotional experience. For some participants, the idea that their loved one may be mentally ill was a source of fear, confusion and worry. Excusing or ignoring their child or relative's unusual behaviors was common. A crisis event triggered action for some parents and family members; for others, engagement with health services was gradual and tentative. Seeking assistance often resulted in participants feeling powerless, overwhelmed and confused. Frustration with the mental health system often occurred in the context of considerable anxiety, exhaustion and anguish regarding their loved one's "descent" (Mohr and Regan-Kubinski 2001, p. 73). For some parents and family members, confirmation that their loved one had a diagnosable mental disorder was a relief. A diagnosis often alleviated guilt and ended a wearying quest for answers. Nonetheless, parents and family members grieved the many, and indeed complex, losses surrounding their loved one's disorder. It was common for parents and family members to feel they had lost, in some sense, their former child or relative. Some participants described dashed or sharply altered hopes for their loved one's future. Parents' and family members' grief typically intensified and remitted over time, evoked by reminders of what they (and their loved one) had lost.

Phenomenology of Loss and Grief: Quantitative Findings

Four studies presented descriptive statistics to substantiate the grief of parents and other family members who had a

child or relative with a mental disorder. Godress et al. (2005) limited their sample to parents. Mother–father dyads were recruited in two other studies (Atkinson 1994; Davis and Schultz 1998). A less homogeneous sample was used by Miller et al. (1990), who recruited parents and other family members.

Very few validated measures have been used to quantify parents' and families' grief in response to their child or relative's mental illness. Two studies used Horowitz, Wilner and Alvarez's (1979) Impact of Event Scale (IES) for this purpose. While the IES (Horowitz et al. 1979) was developed to assess current subjective distress for stressful life events, the scale has been used to assess grief in response to bereavement (e.g., Dyregrov and Matthiesen 1987; Horowitz et al. 1981) and other losses (e.g., injuries, trauma, parent reactions to their child's intellectual disability or Schizophrenia) (e.g., Bruce et al. 1994, 1996; Dyregrov and Matthiesen 1987; Horowitz et al. 1980; Kaltreider et al. 1979). The IES (Horowitz et al. 1979) comprises two subscales that measure Intrusion (e.g., invasive thoughts, images, emotions, repetitive behaviors) and Avoidance (e.g., cognizant avoidance of event-specific thoughts, feelings and situations). In reference to an experienced stressful life event, participants rate the extent to which each item was true of them in the preceding week on the following scale (0 = *not at all*, 1 = *rarely*, 3 = *sometimes*, 5 = *often*). The scale has been shown to possess adequate reliability (e.g., Horowitz et al. 1979; Perkins and Tebes 1984; Zilberg et al. 1982) and can discriminate between bereaved and non-bereaved populations (Perkins and Tebes 1984).

Miller et al. (1990) modified an existent measure to quantitatively assess families' grieving. The Mental Illness Version of the Texas Inventory of Grief (MIV-TIG; Miller et al. 1990) is an adaptation of Faschingbauer et al.'s (1977) Texas Revised Inventory of Grief (TRIG). The TRIG (Faschingbauer et al. 1977) measures grief in response to the death of a relative. The MIV-TIG (Miller et al. 1990) is a 24-item scale comprised of two parts. Part one consists of eight items that assess respondents' initial grief in response to their relative's mental illness. Part two comprises 16 items that measure current grief. Participants respond on the following scale (5 = *completely true*, 4 = *mostly true*, 3 = *sometimes true*, 2 = *sometimes false*, 1 = *completely false*). Higher scores indicate greater grieving. The scale yields adequate reliability; alpha coefficients of .82 and 92 were obtained for part one and two respectively, while the split-half correlation for part two was .89 (Miller et al. 1990). Miller et al. (1990) identified a weaker split-half for part one (.59).

Using the IES (Horowitz et al. 1979), Davis and Schultz (1998) identified grief in 16 parent dyads who had an adult child with Schizophrenia. Godress et al. (2005) similarly used the IES (Horowitz et al. 1979) to capture the grief reaction of 62 mothers and nine fathers of an adult child with Schizophrenia, Bipolar disorder, Schizoaffective disorder or another mental illness. Consistent with the researchers' (Davis and Schultz 1998; Godress et al. 2005) conceptualizations of grieving, reminders of the loss of having a child with a mental illness triggered in parents intrusive and avoidant processes. Davis and Schultz (1998) also adapted an Experience of Stress Scale (developer not specified) to measure parents' current distress when thinking back to when they realized their child had a mental illness. Participants were required to indicate current distress on a 1–100 thermometer scale. Davis and Schultz' (1998) results indicated that reminders of the loss—in this case, recalling the time of diagnosis—was a source of marked distress.

Similarly, participants in Miller et al.'s (1990) study reported they were currently grieving their relative's mental illness. This was evidenced by considerable proportions of respondents endorsing items as *completely true* or *mostly true*. At least half the sample reported greatly missing the way their relative used to be (68%), feeling upset when contemplating how their relative could have been if not for the disorder (56%) and perceiving their relative's illness as unfair (51%). The same proportion of participants found the item *no one will ever take the place that he/she used to have in my life* completely or mostly true.

Atkinson (1994) obtained similar results when using the MIV-TIG (Miller et al. 1990) to measure grief of parents who had a child with Schizophrenia. Mean scores on both parts of the instrument were comparable to averages reported by Miller et al. (1990). Godress et al. (2005) reported similar statistics when part two of the MIV-TIG (Miller et al. 1990) was administered to a parent sample. Godress et al. (2005) also reported moderate correlations between scores on the MIV-TIG (Miller et al. 1990) and IES (Horowitz et al. 1979) total and subscale scores, which suggests both measures may tap the one grief construct.

From these findings, inferences can be made regarding the pattern of parents' and families' grief reaction. The majority of participants in Miller et al.'s (1990) study did not experience grief when first learning of their relative's diagnosis; though, two-fifths (41%) reported disturbed sleep and 35% indicated impaired work functioning. A greater proportion of family members reported current grieving in response to their relative's disorder (Miller et al. 1990). Similarly, Atkinson's (1994) participants reported significantly greater current grief, compared to their initial grief reaction. Atkinson (1994) also compared parents' grief with the grief of parents whose child had died or developed an organic personality disorder following head trauma. Parents of a child with Schizophrenia

reported a distinct grieving pattern; initial grief was significantly lower than the other two groups, yet these parents reported significantly higher ongoing grief (Atkinson 1994).

These findings appear converse to those reported by Godress et al. (2005). Godress et al. (2005) obtained negative correlations between scores on two grief scales (Horowitz et al. 1979; Miller et al. 1990) and years since diagnosis. To further investigate the occurrence of prolonged grief in parents who had a child with a mental disorder, Godress et al. (2005) divided their sample into five cohorts based on years since diagnosis. Inspection of each cohort's MIV-TIG (Miller et al. 1990) and IES (Horowitz et al. 1979) scores indicate a seemingly obvious trend; parents' grief increased in the year following diagnosis, abated 3 years postdiagnosis, rose again in the fifth year and decreased over time thereafter (Godress et al. 2005). However, the only significant differentiation in grief scores occurred between the 1 year postdiagnosis cohort and parents in the cohort where more than 10 years had elapsed, as indicated by IES Intrusion scores (Horowitz et al. 1979). On the MIV-TIG (Miller et al. 1990), parents' grieving 1 year and 4–5 years postdiagnosis was significantly higher than the grief response of parents at more than 10 years postdiagnosis. Godress et al. (2005) recognize, however, that small and unequal group size has implications for the validity of any conclusions drawn from these data.

There appears to be some consensus in these quantitative studies that parents' and families' grief in response to their child or relative's mental illness is significant and complex. Findings by Miller et al. (1990) and Atkinson (1994) provide evidence for the argument that parents and families experience prolonged grief in reaction to their relative's illness. Miller et al. (1990) suggested that the tendency for families to experience minimal grief at the onset of their relative's disorder and more grief as time passes is due to difficulties mourning an ambiguous loss. Miller et al.'s (1990) suggestion is consistent with findings reported in qualitative studies (e.g., Eakes 1995; Jones 2004; Ozgul 2004).

Miller et al. (1990) and others (e.g., Atkinson 1994) propose that findings pertaining to parents' delayed grief may also reflect the snowball of losses families experience as their relative's illness progresses. The very course of mental illness—symptoms are likely to intensify and remit in an often cyclical manner—may shape, or contribute to, parents' and families' grief (Atkinson 1994). Indeed, this hypothesis was supported in a number of qualitative investigations (e.g., Eakes 1995; Ozgul 2004; Tuck et al. 1997). Atkinson (1994) and Miller et al. (1990) also suggested that parents' and families' grief is often delayed because the implications of their relative's diagnosis are not immediately apparent. Parents and family members may, for instance, need time to understand the magnitude of their loss (Atkinson 1994; Miller et al. 1990).

The way in which participants learned of their child or relative's mental illness may also account for a delayed grief reaction (Atkinson 1994). In Atkinson's (1994) study, parents whose child had died of chronic illness or sustained head trauma were told of their child's prognosis within 24 h–2 weeks of the incident. By contrast, parents of a child with Schizophrenia learnt of their child's diagnosis over a long period; only one dyad was told their child had Schizophrenia within a year of their child's first psychotic episode (Atkinson 1994). The typical process by which parents in Atkinson's (1994) study learnt of their child's disorder may explain why they experienced less initial grief and more ongoing grief, as the ramifications of their child's illness became apparent.

In summary, four quantitative studies have relied upon two key measures—one a measure of grief in response to familial mental illness (MIV-TIG; Miller et al. 1990) and the other an index of subjective distress for stressful life incidents (IES; Horowitz et al. 1979)—to substantiate parents' and family members' grief in response to their child or relative's mental disorder. Study findings were largely consistent; participants reported experiencing grief in reaction to their loved one's condition. Using the IES (Horowitz et al. 1979), two studies (Davis and Schultz 1998; Godress et al. 2005) reported that parents experienced intrusive thoughts and feelings about their child's disorder, in addition to engaging in avoidance behaviors. Atkinson (1994), Miller et al. (1990) and Godress et al. (2005) used the MIV-TIG (Miller et al. 1990) to demonstrate that parents and family members continued to experience emotional distress regarding their child or relative's mental illness, preoccupation with their loved one, and difficulty accepting their loved one's disorder. These processes are congruent with current conceptualizations of grieving.

The reviewed quantitative studies also offered insight into the possible trajectory of parents' and family members' grieving. Two studies (Atkinson 1994; Miller et al. 1990) yielded consistent results; parents and family members appeared to grieve more as time progressed. One study (Atkinson 1994) showed that parents of an adult child with Schizophrenia experienced greater ongoing grief than parents whose child had died or developed an organic personality disorder following a head injury. Converse to these findings, while eyeballing Godress et al. (2005) data gives the impression that parents' grief fluctuated over time, statistically significant results suggest that parents grieved less as time since diagnosis elapsed. The authors share some perceptive hypotheses concerning the course of parents' and family members' grief reaction.

Outcomes of Loss and Grief

There is a paucity of research examining the consequences of grieving a child or relative's mental illness. One study by Godress et al. (2005) investigated the relationship between parents' grief and their physical and mental health and well-being, parent–child attachment and affective experiences within the parent–child dynamic. Overall, parents' MIV-TIG (Miller et al. 1990) and IES (Horowitz et al. 1979) scores were significantly inversely correlated with global, physical and psychological health summary scores on the Medical Outcomes Study 36-Item Short-Form Health Survey (MOS SF-36 Health Survey; Ware 2001). Low scores on both grief measures were significantly associated with a secure parent–child attachment style, measured via the researchers' adaptation of the Attachment Styles Measure (Simpson 1990). Higher grief scores were significantly related to an anxious/ambivalent attachment mode. Using a non-published scale, Godress et al. (2005) examined the association between parents' grief and the frequency with which parents rated the occurrence of positive and negative emotions in the parent–child relationship. Positive parent–child affective exchanges were significantly inversely correlated with all indices of parental grief. There was a significant positive association between parents' grief and frequency of negative affect in the parent–child relationship. Godress et al.'s (2005) data imply that parents' grief in response to their child's mental illness has negative implications for parents' physical health status and psychological well-being, as well as affecting interactions with their child.

Some of the qualitative research included in this review makes reference to other aspects of parents' and family members' experience of having a loved one with a mental illness. While these studies do not purport to investigate the implications of parents' and families' grief for various outcomes, findings do suggest that parents and family members who experience grief may also experience other strong (and often negative) emotions. Fear has also been identified as a common reaction to a loved one's mental illness (e.g., Mohr and Regan-Kubinski 2001; Ozgul 2004). Mohr and Regan-Kubinski (2001) observed that parents' fear was often nonspecific and pervasive, ranging from "fear of everything, of what was happening, of the unknown, a fear of oneself, or of one's own emotions" (p. 74). Reviewed studies also described parents' guilt, which appears to be tied to perceived inadequacy as parents, shame, self-accusation and feeling complicit in the development of their child's mental disorder (Mohr and Regan-Kubinski 2001; Osborne and Coyle 2002). Osborne and Coyle's (2002) findings suggest that guilt may prompt parents to blame themselves or each other for their child's disorder. Blaming oneself or one's partner for a child's mental illness may have negative implications for the parent relationship; indeed, one mother commented that partner blame could create tension that had the potential to "pull relationships apart" (Osborne and Coyle 2002, p. 312). Parents in Eakes' (1995) and Ozgul's (2004) research reported feeling anger, frustration, hopelessness, hurt and confusion. Ozgul (2004) also described parents' deep resentment of the unfairness of their child's mental disorder. Mohr and Regan-Kubinski (2001) also found that some parents perceived their relationship with their child to have altered since the illness onset.

To summarize existent findings, one quantitative study (Godress et al. 2005) has found that the intensity of parents' grief in response to their child's disorder affected their own physical and psychological well-being. Intense grieving was significantly associated with an anxious/ambivalent parent–child attachment, as well as more negative and less positive affect between parent and child. While the reviewed qualitative studies did not specifically explore the outcomes of parents' and family members' grieving, it can be inferred that participants who grieved their loved one's mental illness may have also experienced a host of negative emotions (e.g., fear, anger, guilt, resentment, hopelessness) and an altered relationship with their ill relative. That said, the extent to which participants' grief is related to these outcomes remains unclear.

Variables Associated with Parents' and Family Members' Grieving

Three studies investigated determinants of parents' and other family members' grief in response to their child or relative's mental disorder. The results of these studies appear mixed. Davis and Schultz (1998) reported that parents' gender did not predict grief (operationalized as distress when thinking or talking about the loss and feeling upset at reminders of the loss). Likewise, number of contact hours with the child did not predict parents' behavioral avoidance or distress when recalling diagnosis; however, the mean number of hours parents spent with the child per week significantly predicted intrusive thinking about their loss experience (Davis and Schultz 1998).

In Miller et al.'s (1990) research, nonsignificant or weak correlations were obtained between family members' current grief reaction and the following predictors: type of mental illness (Schizophrenia vs. Bipolar disorder), relation to the person with a mental illness (parent vs. sibling), whether or not the family member resided with their relative, number of times the relative had been hospitalized, age of illness onset, illness duration, time since last hospitalization, strength of family member's relationship with the relative and family member's degree of financial, emotional or daily responsibilities for their relative. Using

a larger sample ($N = 225$), Solomon and Draine (1996) conducted a hierarchical multiple regression to determine the predictive function of family demographics, mental illness severity, social support, objective and subjective burden for family members' MIV-TIG (Miller et al. 1990) scores. In contrast to Miller et al.'s (1990) data, family member attributes, social support and burden significantly predicted participants' grief (Solomon and Draine 1995). At the variable level, greater grief was significantly associated with being white, having less education, having a relative who had been mentally ill fewer years, owning a smaller social network, receiving more extensive emotional support, being in crisis, not having the ill relative reside with the respondent and perceiving greater subjective burden (Solomon and Draine 1996).

In summary, results of three quantitative studies that investigated the prediction of parents' and family members' grief in response to a child or relative's mental disorder were inconsistent. For parents in Davis and Schultz's (1998) research, the number of contact hours parents spent with their child predicted the frequency of intrusive thoughts pertaining to their child's disorder. Solomon and Draine (1996) found that participants' grief was predicted by parent or family member attributes (ethnicity, education level, size of social network, degree of subjective burden, concurrent life stressors) and characteristics of the ill child or relative (duration of mental illness, living arrangements). Miller et al.'s (1990) research yielded nonsignificant or weak correlations between grief and patient and family member attributes.

Discussion

Methodological Issues

Research investigative of parents' and family members' grief in response to their child or relative's mental disorder has undergone important development in recent years. Nonetheless, as perhaps evidenced by the small number of studies included in this review, studies concerning parents' and families' loss and grief in response to a loved one's mental illness are few. In terms of methodological shortcomings, the reviewed studies were cross-sectional. This is arguably a limitation, given that the course of parents' and families' grief over time cannot be thoroughly examined. Samples were, for the most part, ethnically homogenous. Also, participants were often recruited from support organizations. It is possible these family members were more active in their coping efforts or, alternatively, more focused on their psychological response to their loved one's illness. Participants in these studies may therefore differ from grieving parents and family members not engaged in support. It is thus suggested that sample composition may compromise the generalizability of findings. Lastly, hypotheses about the relationship between grief and other variables were often tested using instruments developed for the purpose of the study and analyzed using rudimentary statistics. Using nonvalidated measures to answer research questions jeopardizes the strength of any conclusions drawn from these data.

Theoretical Issues

A significant proportion of research on parents' and family members' grief in reaction to a child or relative's mental illness does not appear oriented within a theoretical framework. In some studies, grief is not operationally defined. One such example is the tendency to interpret findings as indicative of parents' or family members' pathological, complicated or complex grief; however, these grief manifestations are often not conceptualized, nor are they disaggregated from normal grief. Moreover, instruments used to assess parents' and family members' grieving do not explicitly operationalize grief. Indeed, the MIV-TIG (Miller et al. 1990) was adapted from Faschingbauer et al.'s (1977) TIG, which endeavors to reflect elements of "unresolved grief" (p. 696) and is based on the developers' clinical observations. The IES (Horowitz et al. 1979) has been widely and effectively used in grief and loss research; however, this measure was developed to assess "current subjective distress for any life event" (p. 209), not grief per se.

These observations broach a wider discussion about the relevance of grief and bereavement theories for parents' and family members' loss and grief in reaction to their child or relative's mental disorder. As discussed, few researchers have explicitly drawn from existent theories and models to operationalize grief. Stress response syndrome (e.g., Horowitz 1986; Horowitz et al. 1979) and cognitive stress theory (e.g., Folkman 2001; Lazarus and Folkman 1984) partially informed Davis and Schultz (1998) and Godress et al. (2005) operational definition of grieving. Grief, according to these authors, involves feeling distressed when thinking and talking about the loss and being upset by reminders of the loss (Davis and Schultz 1998; Godress et al. 2005). Parents who participated in these studies reported experiencing psychological processes consistent with these researchers' grief conceptualization. Many of the reviewed qualitative studies also chronicled parents' and family members' reports of continuing to experience intrusive emotions and thoughts about their child or relative's mental illness. Often, these psychological processes were activated when participants were reminded of their loss. Important milestones for their child or relative (e.g., birthdays, expected year of

graduating from high school or university) were commonly cited as triggers for grieving. Moreover, Mohr and Regan-Kubinski (2001) identified themes in parents' accounts that they interpreted as symptomatic of posttraumatic stress. The authors' inferences stemmed from two parents' reports of vivid, distressing memories—sometimes experienced as nightmares—of when their child was first hospitalized. This dyad's experience also appears consistent with grief conceptualizations that incorporate Horowitz et al. (e.g., Horowitz 1986; Horowitz et al. 1979) and Folkman et al.'s (e.g., Folkman 2001; Lazarus and Folkman 1984) theoretical frameworks. As such, the reviewed studies offer tentative support for the applicability of cognitive stress theory (e.g., Folkman 2001; Lazarus and Folkman 1984) and stress response syndrome (e.g., Horowitz 1986; Horowitz et al. 1979) to the current phenomenon.

Upon reviewing the existent research in this field, it seems that traditional psychoanalytic perspectives on grief and bereavement may have some relevance to the experiences of parents and family members who have a child or relative with a mental illness. Freud (1917/1957) and Lindemann's (1944) proposal that grief is the breaking of emotional bonds to the lost object or person may be applied, to some extent, to participants' experiences. In the case of mental illness, the lost object—that is, the premorbid child or relative—is still present in the mourner's life, although perhaps changed (Jones 2004). The reviewed studies clearly illustrated participants' grief for the loss of their former loved one. Participants' experiences may reflect Freud (1917/1957) and Lindemann's (1944) idea that grief involves a process of emotional detachment from the lost (or premorbid) person. The experiences of some participants appeared similar to some of Worden's (1982, 1991) grief tasks, particularly the process of working through emotional and behavioral pain. Bowlby (1980) conceptualized grief as an attachment process and indeed, parents and family members' experiences were often aligned with Bowlby's (1980) grief phases (see also Rothaupt and Becker 2007; Tedeschi and Calhoun 2004). Yearning and searching, for example, seemed particularly common in Miller et al.'s (1990) sample, with 68% of participants reporting they greatly missed the way their relative used to be and 50% endorsing the item *no one will ever take the place that he/she used to have in my life.*

Contemporary grief and bereavement models may also have relevance for understanding loss and grief in the context of familial mental illness. As discussed, Stroebe and Schut's (1999) dual process model of coping with bereavement (DPM) describes grief as an oscillatory process; the individual shifts between attempting to process the loss (loss-orientation) and attempting to master challenges that stem from the loss (restoration-orientation). Prolonged or complicated grief is a disturbance to this oscillation process (Stroebe and Schut 1999). In the reviewed studies, participants' emotional response to having a loved one with a mental illness was often in the context of endless caregiving duties (e.g., Eakes 1995; Tuck et al. 1997). As such, parents' and family members' experience may reflect Stroebe and Schut's (1999) loss-orientation/restoration-orientation grief conceptualization. Based on their findings, Osborne and Coyle (2002) speculated that parents who have difficulty acknowledging the loss of their child to Schizophrenia may stagnate in restoration-orientation.

Other cognitive perspectives of grieving that may have applicability to participants' experiences include the construction (and reconstruction) of meaning (Neimeyer 2000, 2003; Neimeyer et al. 2001). Neimeyer and colleagues (e.g., 2000, 2001, 2003) suggest that individuals often have difficulty integrating the loss into their own system of meaning. Difficulty integrating the loss may result in the individual feeling shocked, anxious or upset. In this model, grieving is conceptualized as a process of sense making in the face of loss; that is, attempting to organize one's loss experience into a narrative structure while simultaneously developing new systems of meaning (Centre for the Advancement of Health 2004; Neimeyer 2000, 2003; Neimeyer et al. 2001). It was apparent from the reviewed studies that many parents and family members sought to make sense of their experience of having a loved one with a mental disorder. Tuck et al. (1997) described caregivers' meaning making experience in some detail; indeed, they include a participant excerpt that illustrates this process well:

> In the sense that OK, you have a child, he's ill, it's no one's fault. It's not his fault. It's not anybody's fault. It just happened. You [sic] just part of some random statistic. It's gonna happen to someone and if you stop asking "why me?" you may be able to move on with this and see what you can find (p. 122).

Findings from the reviewed studies may also be interpreted in the context of a more general cognitive paradigm. Gluhoski (1995) writes that grief impinges upon an individual's core cognitions about self, word and future. In the reviewed research, parents and family members expressed an array of negative thoughts about their self-worth. As previously discussed, blaming oneself for their loved one's difficulties or perceiving oneself as an incompetent parent (or caregiver) was common (Mohr and Regan-Kubinski 2001; Osborne and Coyle 2002; Tuck et al. 1997). Some participants' responses were suggestive of shifted world views, particularly in their quest to understand why their loved one developed a mental illness (e.g., Tuck et al. 1997). It was very clear from parents and family members' responses that having a child or relative with a mental

disorder dramatically affected their views about the future. Indeed, participants frequently described the pain of relinquishing expectations and hopes for theirs and ultimately their loved one's future (e.g., Osborne and Coyle 2002; Ozgul 2004; Wiens and Daniluk 2009).

In summary, progress has been made in interpreting parents' and family members' grief in response to their loved one's mental illness within existent grief and bereavement theory. The role of intrusive and avoidant processes for participants' experiences has been explicitly examined by some (e.g., Davis and Schultz 1998; Godress et al. 2005); findings suggest that stress response syndrome (Horowitz 1986; Horowitz et al. 1979) and cognitive stress theory (Folkman 2001; Lazarus and Folkman 1984) may have relevance for parents' and family members' grieving process. Osborne and Coyle (2002) discussed participants' experience of having a child or relative with a mental illness within Stroebe and Schut's (Stroebe and Schut 1999) DPM, and suggested that complications may occur if parents have difficulty shifting between the coping modes. While the applicability of traditional grief work hypotheses (e.g., Freud 1917/1957; Lindemann 1944), Bowlby's grief phases (Bowlby 1980), meaning construction and reconstruction (Neimeyer 2000, 2003; Neimeyer et al. 2001) and broader cognitive perspectives on grief and loss (e.g., Gluhoski 1995) for the current phenomenon is yet to be empirically examined, it appears that existent theoretical perspectives may have some relevance.

Opportunities for Further Research

There is an arguably great need to enhance current understanding of how parents and other family members experience their child or relative's mental illness. Loss and grief is one component of families' experience that certainly warrants further study. As discussed, there is a paucity of research examining the applicability of traditional grief and bereavement theories for family members' grief reaction. Further research is needed to bridge this knowledge gap. Operationalizing and validating parents or family members' grief in the context of prominent theoretical frameworks should be a priority for future research.

Research investigative of families' experience of their relative's mental disorder is heavily focused on the experiences of aging parents, often mothers, in relation to their adult child (Baronet 1999). Few studies have investigated the impact of a child's mental illness on parents when the child is an actual child; that is, prior to their reaching adulthood. As such, despite a growing knowledge base concerning the consequences of mental illness for the family, there is minimal understanding of how parents respond to, and experience, their child's or adolescent's disorder. Little is known, for example, about the grieving process of parents who have a child or adolescent with a mental health condition. This paucity of research is both significant and problematic, given the sizeable proportion of mental disorders that develop during childhood and adolescence (Diagnostic and Statistical Manual of Mental Disorders, Text Revision, American Psychiatric Association 2000). Research has also found that children and parents exert profound influences over each other (e.g., Cummings and Davies 1995; Osofsky 1971; Parker et al. 1992); it seems, therefore, reasonable to postulate that parents' psychological reaction may impact the course of their child's mental health condition. Further research may focus on investigating, via quantitative and qualitative methods, whether parents of minor children experience grief in reaction to their child's mental illness. Research concerning parents of children and adolescents with a mental illness would facilitate a better understanding of parents' "real time" grief as their young person's disorder manifests. Such research would also enable comparisons between the grief of older parents who have an adult child with a mental illness and the grief of parents who have a child or adolescent with a mental illness.

In addition to examining parental grief in the context of child and adolescent mental illness, it is recommended that future research endeavors to sample from a broader parent demographic. Recruiting parents from various ethnic and cultural groups and inviting participation from parents who are not engaged in support organizations would increase the generalizability of findings. Extending inclusion criteria from parents who have a child with Schizophrenia to parents who have a child with a mental disorder would also facilitate a more representative sample. Given the disproportionate number of mothers in the reviewed studies, it is also recommended that future research about parents' grief experiences engage fathers of children or adolescents with a mental illness.

Longitudinal studies are needed. This type of research would enable researchers to better understand the course of parents' grieving. Longitudinal studies would be particularly useful for following up cross-sectional data that suggest parents' grief fluctuates over time and is exacerbated by reminders of their loss. Longitudinal research would offer important insights into the role of grief for parents' adjustment and interpersonal relationships. It would also complement, and expand upon, previous research that examined determinants of parents' grief reaction.

Future research might clarify the relationship between parents' grief experience and various outcomes. One study (Godress et al. 2005) used both validated and nonvalidated measures to illustrate the association between parents' grief and their physical health, psychological well-being and

relationship with their child. Future research may aim to replicate these findings using validated assessment tools. It may also be useful to investigate the role of grief for parents' spousal relationships, and also their interactions with other family members (e.g., other children).

Given the inconsistency of findings presented in the current review, future research may seek to identify risk factors for parental grief in the context of child mental illness. Increasing the heterogeneity of parent samples would enable researchers to more comprehensively investigate whether demographic variables (e.g., type of diagnosis, age of child, ethnicity, engagement with support organizations) predict parents' grieving. Future studies may also investigate the role of other variables for the intensity of parents' grief reaction; these predictors could be theoretically driven and may include, for example, personality type, coping style, degree of familial cohesion and parents' own perceptions of mental illness.

Despite the increasingly documented finding that parents and family members grieve their child or relative's metal illness, grief interventions are sparse. Researchers have, however, made treatment recommendations based on clinical observations and research data (e.g., Jones 2004; Marsh 1999; Miller 1996). The absence of grief interventions for these families is problematic, given that there is preliminary evidence for the association between high levels of parent grief in response to their child's mental disorder and poorer parental physical and psychological well-being (Godress et al. 2005). Moreover, parents' grief may have negative implications for their relationship with their child (Godress et al. 2005). MacGregor (1994)—a parent of a child with a mental illness—reflected that

> Mental health professionals must not continue to ignore this issue. Parents of mentally ill children need education about and confirmation of their grief. They need information about their child's illness to address their feelings of powerlessness and decrease their sense of guilt….If normal grief as a response to mental illness is not recognized in parents, then many of them are being misunderstood and misaddressed at a core level (pp. 161,165).

Thus, an arguably crucial avenue for further study is intervention; more research is needed to identify those parents and family members for whom therapy would be of benefit and to develop theoretically driven treatments that can be piloted, administered and evaluated.

Conclusion

This review has presented current knowledge of parents' and family members' grief in response to the psychological loss surrounding their child or relative's mental disorder. Based predominantly on the experiences of aging parents and their mentally ill adult children, research findings consistently indicate that parents and family members grieve their loved one's mental illness (Atkinson 1994; Davis and Schultz 1998; Eakes 1995; Godress et al. 2005; Jones 2004; Miller et al. 1990; Mohr and Regan-Kubinski 2001; Osborne and Coyle 2002; Ozgul 2004; Solomon and Draine 1996; Tuck et al. 1997; Wiens and Daniluk 2009). This grief has been documented as complex and protracted (e.g., Atkinson 1994; Davis and Schultz 1998; Eakes 1995; Mohr and Regan-Kubinski 2001; Ozgul 2004), it appears partially influenced by demographic, situational and psychological variables (Davis and Schultz 1998; Miller et al. 1990; Solomon and Draine 1996) and has been linked to parents' physical health, psychological well-being and relationship with their ill child (Godress et al. 2005). Despite the significant contribution of these earlier studies for present understanding, research in this field is sparse; furthermore, methodological limitations obstruct robust interpretation of some key findings. Grief and loss in the context of familial mental illness is a topic that clearly requires further study. Additional research would unveil important and as yet unanswered questions about parents' and family members' grieving process. Greater knowledge of this complex familial experience would facilitate the development and implementation of evidence-based therapeutic support for these families.

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