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ORIGINAL PAPER

Youth Mental Illness and the Family: Parents' Loss and Grief

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Abstract Parents and family members whose adult child or relative has a mental illness endure significant losses, to which they respond with grief. Such grief may negatively affect family members' physical and psychological health and also the relationship with their relative. Yet, research in this field is sparse. Very few studies have examined parents' loss and grief in the context of the patient being a child or teen. It is not clear the extent to which parents' loss and grief in response to their child or adolescent's mental illness is similar or different to the accounts of older parents and family members caring for an adult relative with major psychopathology (e.g., Schizophrenia, Bipolar disorder). Parental loss and grief is not often addressed in child and adolescent mental health services' provision of care; alarmingly, little is known about how best to support parents who access these services. The present study aimed to bridge this knowledge gap and identify the therapeutic needs of this younger parent population. Comprehensive interviews were conducted with 14 parents and one custodial grandparent of a youth aged 18 years or younger who was currently attending a child and adolescent mental health service. An inductive thematic analysis identified six themes; parents' narrative of finding out, profound and pervasive loss, complex grief, waning support, the challenges of caregiving and a call for assistance. It can be inferred from these results that youth mental illness can constitute a source of loss and grief for parents. Participants' loss and grief was largely consistent with the experience of families caring for an adult relative with major psychopathology. Opportunities for mental health practitioners to support families' loss and grief were identified. Further studies are needed to enhance understanding of this complex and, to a large extent, ignored familial experience. Results do underscore the importance of clinicians acknowledging parents' loss and grief and working directly with this experience over the course of youths' treatment, perhaps in conjunction with family psychoeducation approaches.

Keywords Youth · Families · Mental illness · Grief · Loss

Introduction

Mental illness affects approximately one fifth of youth worldwide (World Health Organization 2000). In the United States, one in every four to five adolescents meet criteria for a mental disorder (Merikangas et al. 2010). Prevalence rates of youth psychopathology in other countries range from 7 to 22 % (e.g., Canino et al. 2004; Eapen et al. 2003; Farbstein et al. 2010; Frigerio et al. 2009; Heiervang et al. 2007; Meltzer et al. 2003). Anxiety disorders are common—Merikangas et al. (2010) cited an aggregate prevalence rate of 31.9 % for any anxiety disorder in an adolescent sample—as are mood, behavior, pervasive developmental, thought and substance use disorders (Corliss et al. 2008). Parental report suggests that 14 % of youth in Australia have psychological problems, 11 % meet criteria for attention-deficit/hyperactivity disorder and 3 % have a depressive or conduct disorder (Sawyer et al. 2000). Mental illness can drastically impair

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youths' ability to function effectively (Corliss et al. 2008; Satcher 2000). These young people are at increased risk of adverse outcomes that include school dropout and incarceration (Corliss et al. 2008). Globally, suicide constitutes the third leading cause of death among teens (World Health Organization 2001). The diversity of these youths' needs and illness severity contribute to the perception that this is a difficult population to treat (Anderson and Mohr 2003).

There is an extensive literature that describes the burden of care incurred by families whose relative has a mental illness (for reviews, see Baronet 1999; Schulze and Rossler 2005). As well as coping with their relative's symptoms and navigating health care and other systems, parents and family members withstand financial hardship, relationship problems, social isolation, prejudicial attitudes of others, disruption to routines, stress, frustration and exhaustion (e.g., Angold et al. 1998; Baker and McCal 1995; Bouma and Schweitzer 1990; Brannan and Heflinger 1997; Corliss et al. 2008; Farmer et al. 1997; Hillege et al. 2006; Johnston and Mash 2001; Yatchmenoff et al. 1998). Parents of youth with psychological disturbance also report worrying about the impact of their child's symptoms on siblings and regret their need to adopt extreme measures to control their child (Delaney and Engels-Scianna 1996). It is well established that caring for a relative with a mental illness places families at greater risk of poorer psychological and physical health (e.g., Aguglia et al. 2004; Jungbauer and Angermeyer 2002; Martens and Addington 2001; Winefield and Harvey 1993).

A less researched aspect of parents' and family members' adjustment is the loss that can accompany a loved one's mental disorder (McElroy 1987; Ozgul 2004; Young et al. 2004). According to a small number of studies (many of which are based on the accounts of older parents caring for adult offspring), family members often feel as though they have lost their relative's former or idealized self (Jones 2004; Miller 1996). Hopes and expectations for theirs (and their relative's) future may be disrupted (Ozgul 2004). Family members can also lose companionship, financial security, roles, faith, competence, routines and control. The losses incurred by families whose relative has psychological difficulties is complex (Jones 2004; Miller 1996) because the "lost" person has not disappeared; rather, they have changed. Family members' loss has been described as nonfinite (Bruce and Schultz 1992), psychic (Miller 1996), ambiguous (Boss 1999) and "intangible, but real" (Young et al. 2004, p. 89).

Research suggests that family members grieve the losses resultant from their relative's mental illness. Their grief symptoms include intrusive thoughts and emotions (Godress et al. 2005), avoidance (Davis and Schultz 1998; Godress et al. 2005), preoccupation with their relative's mental illness and difficulties accepting their circumstances (Atkinson 1994; Godress et al. 2005; Miller et al. 1990). Families' grief has also been described in several qualitative studies (e.g., Jones 2004; Mohr and Regan-Kubinski 2001; Osborne and Coyle 2002; Ozgul 2004; Tuck et al. 1997; Wiens and Daniluk 2009). Because this type of loss is ambiguous (Boss 1999) and nonfinite (Bruce and Schultz 1992), family members' grief rarely subsides over time; symptoms often persist, intensifying whenever they are reminded of what is different (Atkinson 1994; Miller et al. 1990). This reaction is consistent with Olshansky's (1962) notion of chronic sorrow, which was first reported in parents of youth with mental retardation. Chronic sorrow has since been identified in parents whose adult child has a mental disorder (Eakes 1995; Pejlert 2001).

Ambivalence is an important part of family members' grief (e.g., Jones 2004; Miller 1996). By definition, mental illness can entail mood disturbance, distressing, socially inappropriate or potentially harmful behaviors, and pervasive functional impairment. Everyday coping with the presence of psychopathology in a child, parent, spouse, sibling or other relative, in conjunction with a related sense of loss, can contribute to family members' experience of complicated and contradictory emotions (Jones 2004; Miller 1996). For example, family members may harbor anger towards their relative; yet, at the same time, feel guilty and ashamed for feeling this way about a loved one who is also an illness victim (Jones 2004). Miller (1996) also notes that the anger felt by patients' family members is often linked to survivor guilt, for siblings particularly. Anger, guilt and shame are likely to be felt concurrent to positive emotions (e.g., love, dedication) (Bland and Darlington 2002; Jones 2004). Generally, to grieve is understood to involve a process of adjusting to, or accommodating a changed reality. In the case of a loved one developing a mental illness, this adaptation seemingly involves family members relinquishing some of their former hopes and preconceptions (for their relative, and for themselves) (MacGregor 1994). The continued presence of the "lost" relative makes it difficult for family members to accommodate new circumstances and modified expectations without feeling like they are betraying their loved one (Jones 2004). In this sense, family members' ambivalence is likely to obstruct their grief process (Jones 2004; Miller 1996; Ozgul 2004).

Family members' loss in relation to a relative's mental illness is not often recognized by their community. As discussed, this type of loss is ambiguous and unending—likely barriers to society acknowledging its occurrence (MacGregor 1994). The stigma attached to mental illness may further inhibit society's (and perhaps even the family member's) acknowledgement of this complex loss (Young et al. 2004). Also, grief is not generally anticipated as part of families' adjustment to their relative's mental illness, and there are no rituals in which the community engages as a way of mourning families' loss (MacGregor 1994). Research suggests that the grief of family members whose relative has a mental illness is prolonged and complicated by ambivalence (e.g., Jones 2004). This type of grief is not easily acknowledged by spouses, children, relatives, friends, colleagues and, as will be discussed in later sections of this paper, health professionals (MacGregor 1994). Some (e.g., MacGregor 1994) have argued that families' experience is disenfranchised (Doka 1989, 2002), in that their loss is not recognized and their right to grieve denied.

Research indicates that grieving an adult child's mental illness may have a detrimental effect on parents' health and the relationship with their child. Godress et al. (2005) used parental self report to investigate the relationship between parents' grief, physical health, psychological wellbeing and the relationship with their child. Participants' grief was negatively associated with their physical and psychological health. Moreover, greater grief was negatively correlated with a secure parent–child attachment and positively correlated with an anxious-ambivalent parent–child attachment. Lower grief was related to more positive affect within the parent–child relationship; conversely, parents who grieved more indicated more negative affect within the dynamic.

Some effort has been made to identify factors that shape family members' grief, and results have been mixed. Parents' gender did not influence grief scores in a study by Davis and Schultz (1998), whilst parents who spent more time with their adult offspring experienced more frequent intrusive thoughts. Solomon and Draine (1996) found that more grief was expressed by family members who were Caucasian, had less education, had an adult relative with a shorter illness duration, possessed a smaller social network, received greater emotional support, experienced concurrent crises, did not reside with the adult relative and reported greater subjective burden. Conversely, Miller et al. (1990) found nonsignificant or weak correlations between similar attributes and families' grief process.

The majority of research on families' loss and grief in reaction to a relative's mental illness has focused on the accounts of participants recruited from support organizations (e.g., NAMI; National Alliance on Mental Illness) or mental health services with which their relative is engaged. Samples often comprise late middle aged parents whose adult child, typically male, has Schizophrenia or Bipolar disorder (for a review of this literature, see Richardson et al. 2011). Any conclusions drawn from these parents' accounts would appear restricted to certain diagnostic categories. The age of the patient has not been a central focus.

Whereas the research base for caregiver strain and youth mental illness is reasonably large, few studies have explicitly focused on the dynamics of parents' loss and grief in the context of child and adolescent psychopathology. It is unclear whether the loss and grief of parents whose youth has a mental disorder is consistent with, or divergent from, the experience of older parents who care for an adult child. Wade (2006) interviewed parents and caregivers of a child aged between six and 11 years who had been diagnosed with early onset Bipolar disorder. Findings suggested that family members' relentless caregiving "obliterated" (p. 891) their sense of self. More recently, Geraghty et al. (2011) analyzed the records of consultations provided by consumer representatives to families of children and adolescents admitted to a youth psychiatric unit. Consistent with prior studies on adult patients and their caregivers, the researchers found that loss and grief featured in these family members' experience. Moreover, additional themes identified by Geraghty et al. (2011) converge with grief symptoms (e.g., guilt, anger).

A number of family interventions have evolved since deinstitutionalization, many of which are based on the assumption that providing family members with information, education, skills and support will reduce caregivers' burden, facilitate their coping, promote illness management and improve patient outcomes (e.g., relapse prevention, symptom reduction) (Lefley 2009). Family psychoeducation (PFE) combines information sharing—typical content includes mental illness symptoms, etiology, course and indicated treatments—with illness management techniques and skills training (e.g., problem solving, communication) (de Groot et al. 2003; Goldstein and Miklowitz 1995; Lefley 2009; Lucksted et al. 2012). There is considerable variability in how FPE is delivered, and to whom (e.g., individual FPE versus multiple-family groups) (e.g., Dixon et al. 2001; Lucksted et al. 2012). There is a large evidence base attesting to the efficacy of FPE for improving family and patient outcomes (Biegel et al. 1994; Lefley 2009; Pilling et al. 2002); indeed, this form of support constitutes one of the key evidence-based treatments for Schizophrenia (Dixon et al. 2001; Kuipers et al. 2002) and also Bipolar disorder (Lucksted et al. 2012). Family education (FE) is another form of targeted support; it is generally briefer than FPE, facilitated by trained consumers (not mental health professionals, as is the case for FPE) and places more emphasis on caregivers' wellbeing (Stephens et al. 2011). Compared to FPE, the evidence base for FE is small; however, studies do support its efficacy for decreasing families' burden, improving relationships and fostering family members' empowerment (Chien et al. 2004; Dixon et al. 2004; Foster 2011; Pickett-Schenk et al. 2006; Stephens et al. 2011). Other intervention models include family psychotherapy (e.g., Dixon et al. 2001), psychoeducation groups provided by services as standard care, and support groups facilitated via advocacy organizations (e.g., NAMI) (Lefley 2009). The evidence base for these latter forms of support is smaller (Lefley 2009).

Much of the literature on the efficacy of FPE is based around adult patients and their families. However, there is growing interest in the development, adaptation and evaluation of FPE for youth with mental illness and their parents or carers (Lucksted et al. 2012). Studies that have evaluated multiple-family groups PFE (MFG-FPE) or individual-family FPE with youth and their families report favorable outcomes; including, decreased family tension and dysfunction, improved service access, greater family member knowledge, skills and support, and more helpful family member attitudes (Fristad et al. 2002, 2003; Sanford et al. 2006). Parents and caregivers have also rated their satisfaction with FPE programs (e.g., Brent et al. 1993). It is important to also acknowledge null findings regarding the efficacy of FPE for younger families (e.g., Ruffolo et al. 2005). It has been suggested that the variability in these treatment studies and methodological limitations make firm conclusions difficult (for reviews, see Diamond and Josephson 2005; Lucksted et al. 2012; Montoya et al. 2011; Ong and Caron 2008).

Youth mental health services are challenged to meet the needs of patients' parents and carers (Scharer 2002; Tarico et al. 1989). The mental health nursing literature attests to the support, information, affirmation, dialogue and collaborative partnership sought by families who access services (Jakobsen and Severinsson 2006; Scharer 2002; Tarico et al. 1989). Contrary to these expectations, research suggests that parents and carers often feel judged, discounted and blamed by their child's treatment providers (e.g., Kerkorian et al. 2006; Scharer 1999; Tarico et al. 1989). Service models that acknowledge parents' expertise on their child and promote parent–practitioner partnerships in the implementation of treatment are considered empowering and effective (Dunst et al. 1988; Scharer 2002). However, youth mental health services' provision of care continues to evolve from a deficit approach that focuses on parents' inadequacies (Collins and Collins 1990). Research underscores the importance of clinicians providing children and adolescents' parents with sufficient information and support, in order to promote a collaborative parent–practitioner relationship (Scharer 2002). The difficulty of this process is recognized, with successful collaboration requiring clinicians to work flexibly as parents' needs change (Scharer 2002). Clinicians' efforts to understand the dynamic needs of their patients' parents is important, and this process may, as Scharer (2002) suggests, "best be accomplished by listening to what they tell us" (p. 622).

It can be difficult for clinicians to identify and respond to the loss and grief of their patients' families (MacGregor 1994; Young et al. 2004). Often, family members' losses are not apparent to the treating team, owing to the fact that, as discussed, this is an ambiguous (Boss 1999), nonfinite (Bruce and Schultz 1992) and disenfranchised (Doka 1989, 2002) loss. Family members' grief can be complicated by ambivalence (Jones 2004; Miller 1996), whereby difficult and conflicting feelings about the relative (e.g., hope and despair, anger and guilt) are likely to obstruct clinicians' ability to detect family members' grief and facilitate their mourning. In turn, loss and grief are not often explicitly included in services' provision of care. As others (e.g., Lafond 2002; Young et al. 2004) have reflected, clinicians are perhaps more likely to interpret family members' grief in its separate components (e.g., anger, shame). A family member's normative grief may be misinterpreted as pathological, and families are likely to feel unheard (MacGregor 1994; Young et al. 2004).

Some effort has been made to understand how clinicians may effectively support families' grief. In some instances, loss and grief is addressed as a module within broader family support programs. Supportive Family Training (Le Gacy 2001) acknowledges the importance of encouraging group members' mourning and implements Lindemann's (1944) guidelines for "grief work". A grief therapy was also introduced by Miller (1996), who adapted Worden's (1982, 2009) tasks of mourning (e.g., making the loss real, facilitating the expression of affect, assisting the individual to live without the deceased and facilitating emotional withdrawal from the deceased) for family members of adults with major psychopathology. The program involves family members telling the story of their relationship with the ill relative; this is intended to make the loss real and promote family members' expression of difficult emotions. In a second, readjustment phase, the therapist works with the family member to facilitate their accommodation of the loss, through other relationships and also via their relationship with the patient (Miller 1996). The efficacy of Miller's (1996) program is seemingly yet to be established. Miller (1996) did, however, implement his therapy with a series of family members; each client indicated having previously engaged with another type of family support (e.g., group psychoeducation), and each felt that this grief work complemented gains made in other programs. Recommendations have been made by others, based on the results of studies that explored the phenomenology of family members' grief; suggestions include providing a space in which families' experience is named as a normal grief reaction to a complex loss, facilitating family members' expression of grief and ambivalence, assisting family members to find meaning in their experience and maximizing support (Atkinson 1994; Bland and Darlington 2002; Godress et al. 2005; Jones 2004; Lafond 2002; Marsh 1999; Mohr and Regan-Kubinski 2001; Osborne and Coyle 2002; Ozgul 2004; Penzo and Harvey 2008; Tuck et al. 1997; Young et al. 2004). These guidelines are mostly based on the accounts of family members whose adult relative has a mental illness. The applicability of these recommendations for parents whose youth has a mental illness remains unclear.

The Current Study

Literature attests to loss and grief of family members whose relative has a mental illness. Of the studies conducted in this field, comparatively few have examined the dynamics of parents' loss and grieving when the patient is a child or adolescent. Whether these parents' process of adjustment is unique to, or consistent with, the loss and grief of family members caring for an adult relative is unknown. It is necessary to clarify whether parents' loss and grief in the context of youth mental illness is similar to the phenomenology of other family members' grief (as described in prior research), or whether the experience of younger families is unique.

The paucity of research on parents' loss and grief during their child's youth (i.e., prior to their reaching adulthood) is an important knowledge gap. Research shows that a parent and child exert powerful influences over each other (e.g., Cummings and Davies 1995; Osofsky 1971; Parker et al. 1992), perhaps more so when a child, parent or both have psychological disturbance (e.g., Falkov and Lindsey 2002). In the case of parents whose adult child has a mental disorder, grief negatively impacts parents' own health and impedes the parent–child relationship (Godress et al. 2005). It is reasonable to postulate that parents' unresolved grief may shape or perhaps exacerbate their youth's mental health condition. In the case of child and adolescent psychopathology, the importance of parents' engagement for treatment outcome has been shown (e.g., Cobham et al. 2010; Jemerin and Philips 1988). This is noteworthy in that parents' unrecognized loss and grief may obstruct their ability to fully engage in their youth's professional care.

Others have offered clinical guidelines for supporting the loss and grief of adult patients' families, loss and grief is sometimes explicitly addressed in family interventions (e.g., Le Gacy 2001), and tailored grief therapies have been proposed for family members of adult patients (e.g., Miller 1996). However, research that investigates the efficacy of these strategies for family members' adjustment appears lacking. Minimal research on the development and evaluation of loss and grief support for family members means an absence of clear guidelines for practitioners. Given the pivotal role that parents play in their youth's daily care and treatment process, clinicians' ability to effectively support these parents' grief seems especially important. There is a need to develop knowledge around the provision of evidence-based grief support for youths' parents and carers.

The aims of this study were twofold. Firstly, we intended to explore the loss and grief of parents engaged with a Child and Adolescent Mental Health Service (CAMHS) because their youth has significant psychological problems. We aimed to confirm whether the loss and grief of parents attending this service was dissimilar to, or consistent with, the experience of parents and other family members adjusting to an adult relative's mental illness. Secondly, by exploring participants' loss and grief, we aimed to determine the therapeutic needs of parents engaged with the CAMHS. Such knowledge might assist clinicians with supporting their patients' parents through this grief process. Study findings could inform further research on the development, trialing and evaluation of grief support for youths' families.

Method

Recruitment Setting

Participants were 14 parents and one custodial grandparent whose youth was attending a CAMHS in Brisbane, Australia. The service provides assessment, treatment and follow up for youth who present with major psychological difficulties that significantly impact their functioning. Multidisciplinary teams provide individual, group, parent and family support, in addition to responding to families' acute needs. We recruited participants from various service divisions, including an inpatient unit, partial hospitalization program and community clinics. No eligibility criteria were stipulated because it was our intention to recruit a sample that reflected the demographic characteristics of families who accessed the CAMHS. Participants were recruited by clinic staff via flyers and word of mouth. Recruitment continued until saturation was reached.

Participants

The sample comprised eleven mothers, three fathers and one custodial grandfather. There was one case in which both mother and father completed a separate interview in reference to the same youth. Participants' ages ranged from 41 to 59 years (mean age = 48.93 years, SD = 6.12 years). Most parents identified themselves as Caucasian Australian; one parent identified himself as being of Aboriginal and Torres Strait Islander origin and one parent identified herself as Thai. The majority of parents ($n = 8$) described their relationship status as separated, five parents were married or in a de-facto relationship and two parents were widowed. Six parents reported previously accessing mental health services for their own psychological difficulties and two mothers reported current mental health problems.

Participants' youth were seven males and seven females who ranged in age from eight to 18 years (mean age = 13.96 years, SD = 2.52 years). International Classification of Diseases (ICD-10; World Health Organisation 1992) mental illness diagnoses included separation anxiety disorder, obsessive compulsive disorder, generalized anxiety disorder, disturbance of activity and attention, anxiety disorder unspecified, adjustment disorder, specific phobia, anorexia nervosa, recurrent depressive disorder, dysthymia, elective mutism, self injurious behaviors, expressive language disorder, receptive language disorder, other childhood disorder of social functioning, Asperger's syndrome and oppositional defiant disorder. Several youth had received additional ICD-10 (World Health Organisation 1992) diagnoses relating to factors influencing health status and contact with health services; including, personal history of congenital malformations, deformations and chromosomal abnormalities, problems related to alleged physical abuse of child, atypical parenting situation, other stressful life events affecting family and disruption of family by separation and divorce. The majority of youth had received more than one diagnosis.

From the date of the interview, youth had been engaged with the service for an average of 3.5 years (range 7.3 months–11.3 years). Occasions of service ranged from six to 341 (median number of occasions = 43). Six youth had been hospitalized at least once in relation to psychopathology. The majority of youth ($n = 9$) were currently prescribed medication for their condition. Pertinent details of each youth's background are presented in Table 1. To aid interpretation of results, each youth is allocated a pseudonym (see Table 1).

Procedure

The first author met with each participant, explained project requirements, obtained informed consent and administered a demographic survey and a comprehensive interview. The measure was developed for the purpose of the study and took approximately 1 h to complete. Interviews were audio-recorded. Once the interview was completed (and with participants' informed consent), we obtained relevant background data on the youth (e.g., occasions of service) from the CAMHS' patient database. This study was subject to full review by relevant university and health services human research ethics committees.

Measures

We developed the interview to thoroughly assess parents' experience of their youth's mental illness. Items examined parents' current reaction to having a youth with a mental illness, as well as their initial response. Questions were organized around the cognitive, behavioral and emotional components of parents' experience. The measure also enquired about parents' social support and coping, their experience of stigma associated with their child's mental illness and perceived quality of accessed care. Importantly, participants were also invited to share their ideas for the type of support likely to benefit parents coping with their youth's disorder. Items included prompts to elicit parents' responses. We sought input from consumer representatives within the CAMHS when developing the interview. The measure is included as an "Appendix".

Data Analysis and Coding

Interviews were transcribed verbatim by the primary author. Responses were subject to an inductive thematic analysis (Braun and Clarke 2006). Consistent with Braun and Clarke's (2006) guidelines, the primary author read each transcript several times and noted initial ideas. The same author then coded participants' responses. The resultant 40 codes were collated into six themes. Themes were reviewed by the primary author to ensure they mapped onto coded excerpts, as well as applying to the broader data set. Each theme was then named. A research assistant not affiliated with the study then coded participants' responses and identified 43 codes. These codes were compared with those identified by the primary author; inter-rater reliability for codes was $\kappa = .76$ ($p < .001$), 95 % CI [.53, .98].

Results

Six overarching themes were extracted from the data.

Tip of the Iceberg: Parents' Narrative of Finding Out

Parents reflected on their initial realization that their child was struggling. For parents of youth with developmental difficulties, this dawning of awareness often occurred during their youth's toddlerhood. These parents were particularly worried about their child's social difficulties. They witnessed their youth's disinterest or discomfort playing with other children. Sam's mother remembered how "he was like a shark, just around the edge, you know, not participating in anything … he was just not the same as other children". Parents of youth whose problems developed later watched them manifest unusual behavior. They usually noticed their child's functional decline, recalling how they increasingly struggled at school and withdrew from friends and family.

Most parents worried. Their anxiety stemmed from an increasing awareness that something was wrong with their child, yet they did not know what it was, why it was happening or how to fix it. As Chelsea's mother recalled, "I was very, very distressed, I was concerned, I thought, 'there's more to this, I need to find out what it is'". By contrast, Tess' mother recognized the similarity between her daughter's behavior and that of her son. The possibility

Table 1 Youth's gender, age, illness background and family composition

Youth's gender[a] and age[b]	Relevant background
Jack (m; 14)	Asperger's syndrome, personal history of congenital malformations, deformations and chromosomal abnormalities. Engaged with service for ~6 years; attended on 40 occasions. No episodes of hospitalization. Current medication. Resides with parents and two siblings. Maternal history of psychopathology
Dylan[c] (m; 17)	Disturbance of activity and attention, expressive language disorder, receptive language disorder, other childhood disorder of social functioning, other stressful life events affecting family and household. Engaged with service for ~11 years; attended on 110 occasions. No episodes of hospitalization. Nil current medication. Only child; resides with parents. Maternal current psychopathology
Tess (f; 14)	Obsessive compulsive disorder. Engaged with service for ~18 months; attended on six occasions. No episodes of hospitalization. Current medication. Parents separated; resides primarily with mother and one sibling. Maternal history of psychopathology
Paige (f; 15)	Anorexia nervosa, recurrent depressive disorder. Engaged with service for ~3 years; attended on 43 occasions. Hospitalized on several occasions and current medication. Parents separated; nil contact with father. One sibling
Tom (m; 16)[d]	Depressive symptoms, self injurious behaviors. Engaged with service for ~18 months. Hospitalized on 4 occasions and current medication. Lives with mother and sibling; father deceased
Lucy (f; 15)	Elective mutism, dysthymia, generalized anxiety disorder. Engaged with service for ~2 years and attended on 341 occasions. Hospitalized once and current medication. Only child; resides with father. Mother deceased
Melissa (f; 15)	Anorexia nervosa, recurrent depressive disorder, anxiety disorder unspecified. Engaged with service for ~2 years and attended on 50 occasions. Hospitalized 3 times and current medication. Resides with parents and one sibling. Maternal history of psychopathology
Chelsea (f; 12)	Anxiety disorder unspecified. Engaged with service for ~4 years and attended on 87 occasions. No episodes of hospitalization. Nil medication. Resides with parents and 3 siblings. Maternal current psychopathology
Matthew (m; 14)	Generalized anxiety disorder, disturbance of activity and attention, separation anxiety disorder. Engaged with service for ~3 years and attended on 40 occasions. Hospitalized once and current medication. Parents separated; resides with mother and one sibling. Nil contact with father. Maternal history of psychopathology
Luca (m; 8)	Attention difficulties. Engaged with service for ~2 years and attended on 30 occasions. No episodes of hospitalization. Current medication. Resides with custodial grandfather
Phillip (m; 18)	Oppositional defiant disorder. Engaged with service for ~3 years and attended on 128 occasions. Hospitalized once. Current medication. Parents separated; resides with mother and two siblings. Nil contact with father
Holly (f; 10)	Adjustment disorder, specific phobia, disruption of family by separation and divorce. Engaged with service for ~1 year and attended on 20 occasions. No episodes of hospitalization. Nil medication. Parents separated; resides with mother. Only child
Catherine (f; 14)	Anxiety disorder unspecified, generalized anxiety disorder, atypical parenting situation, other stressful life events affecting family, disruption of family by separation and divorce, problems related to alleged physical abuse of child. Engaged with service for ~2.5 years and attended on 50 occasions. No episodes of hospitalization. Nil medication. Parents separated; resides with father and two siblings
Sam (m; 13)	Asperger's syndrome, other stressful life events affecting family and household. Engaged with service for ~2 years and attended on 40 occasions. No episodes of hospitalization. Nil medication. Parents separated; resides with mother and one sibling. Nil contact with father

[a] *m* male, *f* female; [b] age in years; [c] both mother and father interviewed separately; [d] missing data

that her daughter may also be experiencing obsessive compulsive disorder filled her with dread:

> She said "they are just thoughts that come into my mind and go away again" and I asked "can you stop them?" and she said "no I can't, they just go away" and I thought "oh God, here we go"

Amidst worrying their youth may have a mental illness, parents had to field questions and comments from others. Day care staff informed some parents that their toddler had difficulty completing basic activities and socializing. Relatives voiced their concern. Parents received phone calls from alarmed teachers. Whilst parents appreciated others' input, these observations compounded their distress. As Jack's mother recalled:

> The teacher he had in kindy and preschool kept notes on his behavior which was fantastic but at the time I couldn't stand her because every day she would give me an earful about what he didn't do … every day

Parents' decision to seek help was usually precipitated by a worsening of their child's symptoms. Learning of their youth's diagnosis was an important aspect of many parents' story. For some participants, being told their son or daughter met criteria for a mental disorder was a relief. The diagnosis explained their youth's behavior and discounted parents' fears they were solely to blame. Chelsea's mother described her relief; "for me, it was just like, thank God, now I know what it is, who cares … now I know it's not me". Other parents were shocked and refused to believe that their youth's behavior was consistent with a mental disorder. Some parents experienced dread; the diagnosis confirmed their fears that this was more than a passing phase. As Lucy's father explained, his daughter's diagnosis was "the tip of the iceberg that sank the Titanic".

Profound, Pervasive Loss

Inherent to most participants' experience was loss. Parents' losses were multiple, and the main types of loss are explored below.

Loss of My Real Child

Parents painted vivid pictures of their child's true nature. Some described how their youth would be without mental illness. Others reflected on how their child was before the illness developed. When reflecting on their "real" child, they spoke fondly. In contrast, parents described how their youth's condition involved the manifestation of behaviors that were shocking, distressing, humiliating, annoying, unpredictable or frightening. Paige's mother described how her daughter "reacted very, very badly, like an insane person, she screamed and fought".

So contradictory were these behaviors to their youth's personality that some parents felt their youth had transformed. In some cases, this metamorphosis involved physical change. However, it was the dramatic shifts in their youth's character that most parents recalled. Phillip's mother described the rapidity of her son's transformation, explaining how "he can go from naught to meltdown within two seconds … Sometimes I can get a sweet child and then I get this horrible, aggressive child that tries to kill me".

Several parents felt that mental illness had robbed them of their youth's former self. Where their child developed difficulties during middle childhood or adolescence, parents felt they had lost the happy youth they knew and cherished (and to whom they related). Paige's mother likened the experience of watching her daughter develop anorexia nervosa to watching a "beautiful young sapling" being strangled by a creeper vine. Parents whose youth had experienced difficulties since toddlerhood described feeling as though they had lost their child's ought-to-be personality. As Matthew's mother reflected "I feel like, sometimes I…think, what would he be like as a person, if…he wasn't going through this?" Jack's mother expressed a similar sentiment when she stated "if he…didn't have Asperger's syndrome he'd be a very placid, easy going child".

Parents often had difficulty reconciling the discrepancy between their youth and their youth's illness. Some participants struggled to maintain a bond with their young person. As Holly's mother reflected, "it's not the Holly I know. That's for sure, it's not the Holly that people generally tell me about, I mean, it's really at odds with who I know her to be". Paige's mother described her struggle to separate her daughter from her daughter's disorder; "that was the hardest time. To try and remember this youth actually loves you inside, there's a little girl who loves you, but she's frightened and she's overwhelmed".

Dashed Expectations: I Thought My Child Would…

Parents had expectations for their child. Like most mothers and fathers, they assumed their youth would follow a normal trajectory of development, have the capacity (and willingness) to engage academically at school, make friends, get invited to birthday parties, maintain good relationships with their parents, develop a positive self concept and learn to regulate their emotions. Some believed that their youth's mental illness had capped their potential, which meant that many of parents' expectations had not been met. Lucy's father simply anticipated that his daughter would have a childhood, and reflected on the impact of her mental illness on this expectation; "there's always been that feeling for me that Lucy's never really had a childhood, and that does leave a hole in me".

My Child's Future: An Uncertain Path

Mental illness jeopardized several parents' dreams for their youth's future. They described a growing realization that the future of which they had hoped for their child may not be feasible. Some parents readjusted their understanding of what their youth's future may hold; often, this vision was not as optimistic. With this reframing also came a loss of certainty and usually, worry. Sam's mother spoke about her anxiety:

> I can try and guide him the best way I can, but when I go, his brother gets married, has a family, what happens to Sam? How's he going to cope? … I do worry about the losses he's going to have in his life, he's going to lose his brother, because his brother's going to get married and have a family, and then Sam's going to have the loss of no children, no wife, maybe no job that inspires him

Loss of Parental Confidence and Control

A number of parents felt powerless to help their child. They tried desperately to intervene by modifying parenting strategies, gathering information and talking to their youth; however, these efforts were usually ineffective. This contributed to parents feeling out of control. As Jack's mother explained "you have control to a certain degree as a parent, about how to raise your children, but when you have a youth with a mental illness you have no idea what to do". Some lost confidence in their ability to parent and found themselves increasingly questioning their own competence.

My Family's Losses

Parents reflected on how their youth's mental illness affected their families' options and decisions. As Jack's mother described, "if Jack didn't have a mental illness our choice in schools would be different, ah, there would be a whole range, there is a whole range of things that would be different in our life". For other parents, ensuring their child received quality care meant a loss of financial security. Several parents resigned from work or changed jobs in order to meet their young person's needs. Others experienced a loss of social engagement. For some parents, their child's illness had meant that time with other family members was comprised. Sam's mother described her loss of memories for her other son's development. Jack's mother described how she missed opportunities to bond with her daughters:

> I feel like I've wasted a lot of time (crying), um, that could have been spent with my children because I was chasing, um, social experiences for Jack … I feel like I've missed, um, I feel like I've missed all that fun time when they're little, I can't remember some of it (crying) … You can't get back that, I think I've grieved that a lot, that you can't get that back, those times when they're little … it's gone

Mental illness affected families in others ways. Some parents described how their other children would react negatively to their relentless focusing on their youth's treatment. For some parents, their child's mental illness had limited the family from doing enjoyable things together, such as going out to dinner, sitting in a cafe or simply leaving the house. A number of parents described a sense of losing their own identity. These participants described feeling changed as a result of being a parent of a child with difficulties. As Jack's mother commented, "I'm a lot more guarded about, I can't, um, sometimes I feel like I can't be my true self".

Complex Grief

Grief was a common reaction to the losses that participants endured. Two central themes were identified from parents' accounts, each of which is discussed below.

The Lived Grief Experience

Parents often yearned for their youth's former or potential self, and longed for the bond they once shared. Several parents described feelings of hopelessness, sadness, shock and numbness. Some felt disappointment and anger. Parents often cried; as was the case for Tom's mother, "yeah, so now I just go home and cry … [I] just sit there, crying". Phillip's mother explicitly acknowledged her grief, commenting "I think you always have that grief; you grieve for what your child could have achieved".

Several participants maintained negative cognitions in relation to their youth's condition. Undoubtedly, at the heart of many parents' anguish was a sense that they were responsible. They questioned their childrearing skills, choice in schools, wondered whether their pregnancy had any bearing on their youth's condition, and entertained thoughts that they had passed this down to their youth. Matthew's mother reflected on her guilt:

> You feel like it's your fault, and, and then you start to believe that it is your fault, even though you know it's not … It still creeps into your mind, in the way you think and you process stuff, and then I, even now, I still feel, um, that it, I feel guilt … Did I cause this in some way through the pregnancy, did I do something? He was induced early, I thought 'oh, did that affect his brain development?'

Tom's mother's guilt was a source of considerable distress; she commented "yeah, I feel guilty all the time … because yeah, when he was young you know (crying) … I feel, always, I feel guilty". It was also apparent that some parents perceived their adjustment to their child's mental illness as abnormal. This was true for Mathew's mother, who was very distressed by thoughts of harming her son to alleviate his suffering:

> I'm afraid of those thoughts, and I'm afraid of, what that means, to be having those thoughts, you know … Something wrong with me, am I going nuts? What's going on with me?

For some parents, realizing their youth may have psychological difficulties and then receiving a formal diagnosis triggered immense sorrow. Several parents described how their emotions had intensified over the years. Other parents experienced pangs of grief which were easily and frequently triggered. Triggers included an escalation in their child's behavior, comparing their son or daughter to other children and being reminded of their child's hospitalization(s). For Jack's mother, watching her son struggle with a task that his peers could accomplish was a source of ongoing grief:

> You never get over it … if a child died, Jack could have died when he was a baby … you would grieve

> and you could grieve but you would eventually come to terms with it, you would … I think you would get over it, not get over it but that you would accept it, you know, that it would stop … at some point the, when, with Jack, with a child with a mental illness, you never get past it (cries) … well I don't know, I've never got past it, because everything, every situation, every experience is new, and you go through the whole thing all over

For Tom's mother, seeing her son's old school photo heightened her yearning for his former self; "I miss him, every time when I walk past his picture I wish I [could] go back (crying)… [to a] long time ago". The same mother described how seeing her friend's toddler made her long for how Tom used to be.

Coping with Grief

Parents drew on a variety of coping strategies. They expressed themselves through creativity, sought company from friends, pursued self help books and relied on family members' support. Parents also coped via seeking reassurance from their youth's treating team. Others were supported by their colleagues. Sam's mother described the importance of self expression for her adjustment:

> I need to express, I need to express, so I wrote and I paint, I always am creating something, and I think that's trying to build positives when I'm just surrounded by negatives most of the time

For Melissa's mother, seeking support from her friends and family was important:

> I've got a lot of good friends, I had a couple [of] girls cooking for me, I've got a best friend, she's a nurse … So she'd come up, you know, people would ring up, and mum and dad were great they came back … She'd take Melissa to therapy some days for me, um, and dad would take (brother) to football and just take the stress out

An important part of parents' coping involved belief in their child's potential. Participants were eager to discuss their youth's strengths, about which they spoke enthusiastically. For many parents, believing in their child's potential meant remaining hopeful that they would get better. As Paige's mother explained, "I learned over that time that all I could do was be positive with her. My job was to keep smiling, [maintain] the optimism, the 'life is really good outside, can't wait till you can come back'". Parents also managed by reflecting on the positives of their situation. For instance, some parents felt their youth's illness taught the family how to communicate. Their child's mental illness had forced other parents to reconsider their family's priorities. For Melissa's mother, this involved limiting each family member's commitments so they could spend time together.

Avoidance was part of most parents' coping repertoire. Parents tried not to entertain certain thoughts. They used exercise, television, housework and socializing as distractions. Jack's mother described her unwillingness to contemplate the negatives, stating "I don't like to hear bad stuff, you don't want to hear the bad stuff". Tess' mother discussed her need to suppress particular thoughts, reflecting that "I have to get rid of that thought because that's, I'm not going there". In several cases, parents avoided their own feelings and thoughts in order to devote their energies to their youth's care.

Waning Support

Some parents felt immensely supported by their family, their child's school and the clinicians involved in their youth's treatment. This was not the case for all, some of whom were single parents and described feeling isolated from support networks. Some parents felt that their extended families attributed their child's disorder to poor parenting. Jack's mother was visibly distraught as she recalled the reaction of two relatives when she tried to manage Jack's disruptive behavior; she described how "the reaction of my sister in laws made me feel like I should be out in jail (crying) … [they gave me an] absolutely, disgusting look".

Parents frequently felt unsupported by their youth's school. This sentiment typically stemmed from either the school's inability to help their child or failure to acknowledge their potential. Parents described instances of their youth being treated differently in the classroom. Some parents felt judged and ostracized by staff. For Jack's mother, it was the teacher's discriminatory behavior towards her son and poor communication with her that exacerbated her distress:

> I went to…clean out, help Jack clean out his desk at the end of the year, and his desk was behind (crying) a big cement pole… for a whole year…he sat behind a big cement pole and (the teacher) would never let me in the classroom…she told me squat about what was going on

Some parents also felt unsupported by the professionals involved in their youth's treatment. They felt practitioners made unfair assumptions about their family. Phillip's mother felt her son's clinicians didn't "expect him to succeed". Melissa's mother felt directly blamed:

> I said to my husband "I'm just going to shut up, I'm not going to say anything at all, because it was we

> were the bad guys", we were in there and we were just like, "what have we done wrong?"

Absence of support led to some parents concealing their youth's mental illness from others. As Jack's mother explained "I wouldn't tell anyone else, because they um … other people have already … Sort of, thrown him off (crying) … thrown him off as a person, as a human being". There were instances where some parents were forced to disclose their child's mental illness, which typically caused anguish. Jack's mother described breaking down when she first publically acknowledged her son's diagnosis; "I just broke down, because I've never … I've never ever said in public that my son has a mental illness, I've said that my son has a disability because it's more acceptable".

Several parents concealed their own reaction to their youth's illness. For these parents, their grief was private, something they attempted to hide. As Paige's mother explained:

> I couldn't cry when there were people around, you can't do that as a parent, and when you're with your son you have to be up, and when you're with your work people it has to be about work, so … in the middle of the night at home I would sob into my pillow

She later elaborated on her struggle to convey this grief to others:

> So I found not talking to people was the only way I could cope with that, because I couldn't explain it to myself, how could I explain it to someone else, and it made me cry, so … I didn't want to cry. My eyes were puffy enough

The Challenges of Caregiving

Most parents had difficulty supporting their child's treatment whilst meeting other responsibilities. Many parents had to leave work to take their youth to therapy. For several parents, their child's management was multidisciplinary and involved attending numerous appointments at different locations. Parents attended meetings at their youth's school. Time spent at therapy, meeting with their child's teachers and managing their youth's behavior limited opportunities for parents to interact with other family members and spend time on their own. Meeting their child's needs was sometimes associated with financial strain. And whilst parents certainly did not resent their involvement in their youth's care, they found this balancing act exhausting and burdensome. Parents' accounts illustrate these challenges. As Lucy's father explained:

> I can't work Monday to Saturday and it's, you know, [an] hour and twenty [minutes] drive each way, so yeah, it's trying too financially, lot more petrol, lots of money [to] take her to appointments to psychologists and psychiatrists so it's affected things

Melissa's mother commented:

> The whole family thing was very disrupted, and then when Melissa got sick it was the same again, like we'd, I'd go to work, I'd leave work, I'd go to the hospital, I'd leave hospital for a meeting, I'd be up there until 9 o'clock at night and she wouldn't want to be alone so (husband) said he'd sleep up there, and then I'd be exhausted…

A Call for Assistance

Participants contemplated the kind support required by parents of youth with psychological problems. There was a consensus that empathic professional support was crucial. Participants commented on the need for clinicians to address parents' self-blame. Others suggested that education around the course of their youth's illness and prognosis may allow parents to develop realistic expectations and plan for the future. Several participants suggested that parents reflect on their expectations for themselves and their youth. Some parents iterated the importance of self care. Most emphasized the value of simply being able to talk.

Parents' accounts underscore these observations. Paige's mother commented on the benefit of positive therapeutic support;

> "It's a chronic case, but she is going to survive this. 100 % of people at 14 get through this, at this stage". And him [mental health professional], um, saying that, meant I could do it. Until someone said that, it was much harder

Holly's mother offered some perceptive comments about the value of self reflection:

> Support people to look at where some of those expectations have come from, what role does the media play in helping us believe, or begin to imagine these dreams for our children, what are these expectations about normal life and where do they come from? Which ones do we subscribe to, and which ones do we want to unsubscribe to?

Parents felt strongly that mental health professionals should recognize parents' grief symptoms as a normal reaction to their youth's condition. Dylan's father emphasized the need for others to acknowledge parents' grief:

> I think the most important thing is that people are made aware of, that they need support, and that's the

> most important thing, that people recognize, and I mean I've gone through this, recognize that loss and grief

These views were often voiced in the context of a broader discussion around society's stigmatization of mental illness, and the need for prejudicial misconceptions to be overturned.

Discussion

This study aimed to explore the loss and grief of a representative sample of parents engaged with a CAMHS because their youth has major psychopathology. We aimed to determine whether the loss and grief of parents whose child or adolescent has a mental illness is similar or different to the experience of adult patients' families, as reported in previous studies. A second aim was to identify the therapeutic needs of parents and family members over the course of their youths' professional care. It was anticipated that this knowledge might provide clinicians with preliminary guidelines for supporting their young patients' parents' grief and adjustment.

To summarize current findings, participants incurred a number of losses associated with their child's mental illness. Losses included loss of their child's former or idealized personality, dashed expectations, loss of certainty about their youth's future, loss of parental confidence and control, loss of financial stability, limited chances to engage with other children, missed opportunities to socialize and loss of self. Participants described symptoms that are consistent with conceptualizations of grief; notably, yearning, cognitions around self blame, hopelessness, guilt, avoidance, anger, disappointment, sadness, crying, numbness, worry, shock and denial. Participants' grief persisted over time and was exacerbated by various milestones and circumstances. Results also highlight parents' mechanisms for coping with their experience and suggest that, in addition to loss and grief, parents frequently endure caregiving challenges and waning support.

Participants' loss, grief and adjustment is similar to the experience of older family members whose adult relative has a mental illness. In the current study, parents' process of understanding their youth had a mental illness was aligned with the experience of parents in Mohr and Regan-Kubinski's (2001) focus groups, whose adult child had Schizophrenia or a major affective disorder. Anguish and guilt were common reactions in both samples. Jones (2004) commented on the ambiguity of family member's loss; similarly, parents in this study reflected on their struggle to reconcile a sense of losing their child's "selfhood" (Miller 1996, p. 634) with the continued presence of their son or daughter. The rapid cycling of some youth's symptoms compounded participants' loss. Parents in others' (Osborne and Coyle 2002; Tuck et al. 1997) research also described a sense of losing their adult child's real self. Participants in the present study described how their child's mental illness impacted their own identity; parents in Tuck et al.'s (1997) research felt similarly, reflecting that their adult child's illness challenged their beliefs about self and jeopardized their efforts to maintain a separate identity. That several parents experienced pangs of grief precipitated by reminders of their loss is consistent with findings by Ozgul (2004), and also Eakes' (1995) identification of chronic sorrow in parents of adults with mental illness. Caregiver strain (notably, fatigue) was identified as a key aspect of participants' experience, and was also identified in others' research with adult patients' families (e.g., Eakes 1995; Tuck et al. 1997). Some parents described feeling unsupported by their youth's treating team, which is consistent with the frustration felt by fathers in Wiens and Daniluk's (2009) study regarding their adult child's mental health care. Wiens and Daniluk (2009) noted the admiration fathers maintained for their child and participants in this research felt similarly; despite their grief, parents believed in their youth's potential.

Concepts within the loss, grief and bereavement literature may have relevance for participants' experience. Consistent with Bruce and Shultz' (1992) nonfinite loss, the losses that participants incurred were ambiguous. Parents' loss of self, for example, is not a tangible event that ends at a specific point in time; rather, this form of loss is both fluid and abstract. The course of participants' grief also resembles Olshansky's (1962) chronic sorrow, in that parents experienced pangs of sadness when reminded of their loss. Precipitants of participants' grief included a worsening of their youth's symptoms, comparing their child to his or her peers, recalling periods of crisis and seeing a child's old school photo. That some parents described feelings of anger or guilt in relation to their child's condition is also consistent with Olshansky's (1962) framework.

It appears that participants' loss and grief in the context of their child's mental illness is socially disenfranchised (Doka 1989, 2002). Results suggest that the degree to which parents felt supported by others shaped their ability to cope with this experience. That some parents concealed their youth's diagnosis from others and felt pressured to keep their feelings hidden is consistent with Doka's (1989, 2002) notion of disenfranchised grief. It could be inferred from current findings that parents' loss is not readily detected by others, and their grief overlooked. MacGregor (1994) also highlights society's failure to recognize and support loss and grief in the context of familial psychopathology. Whether this oversight reflects society's stigmatization of individuals with mental illness and their families is unclear.

Based on these results, inferences can be made about the therapeutic needs of parents engaged with youth mental health services. Participants' narrative about their process of understanding that their child had a mental illness was central to their experience. As such, parents are likely to benefit from having the opportunity to share their story (and reflect on its significance) to clinician(s) coordinating their child's care. Parents experienced complex loss in relation to their youth's mental health condition. Assisting parents to name what is gone or changed, as well as normalizing their sense of loss, may be a useful undertaking for the treating team. Results suggest that there is an opportunity for clinicians to encourage parents to express their grief, including difficult and conflicting emotions (e.g., love and resentment). Normalizing parents' ambivalence, and providing information about the common trajectory of grief in this context, could be worthwhile. Part of clinicians' support might also involve addressing parents' cognitions around self blame. Parents' mechanisms for coping with their experience varied, and the majority of participants described struggling to balance their child's needs with work and family commitments. These results imply that support around self care and coping may also be beneficial. Some participants reported difficulties liaising with their child's school or treating team, and described instances of feeling blamed and discounted. As such, it would seem that there is a need for clinicians to support parents around navigating these systems; particularly, facilitating parents' ability to assertively communicate their questions and concerns.

As discussed, others (e.g., Atkinson 1994; Bland and Darlington 2002; Godress et al. 2005; Jones 2004; Lafond 2002; Marsh 1999; Miller 1996; Mohr and Regan-Kubinski 2001; Osborne and Coyle 2002; Ozgul 2004; Tuck et al. 1997; Young et al. 2004) have suggested ways in which mental health professionals might support grief of adult psychiatric patients' families. Their recommendations include reframing parents' behavior as a valid loss and grief process, helping families to make sense of, or find meaning in their experience, validating the loss and making it real, facilitating the expression of grief, working sensitively with parents' ambivalence, assisting family members to accommodate the loss via relationships and mobilizing supports. Based on the needs of participants in this study, others' recommendations seemingly have potential for supporting grief of parents whose youth has a mental illness. For instance, the importance of working sensitively with family members' ambivalence was underscored by Jones (2004) and Miller (1996); this also seems important for supporting youths' parents, based on current findings. Results suggest that youths' parents are likely to also benefit from didactic components of psychoeducation (e.g., problem solving, communication skills). It may be that combining FPE work with principles of grief therapy would more fully meet the needs of youths' parents and caregivers. Others have suggested a similar approach in the context of supporting adult patients' families (e.g., Miller 1996).

The chief limitation of this study is the relatively small sample. Although recruitment continued until the point of saturation, a sample size of 15 parents may compromise the generalizability of findings. The disproportionate number of mothers who participated means that it is difficult to generalize these results to the experience of fathers whose child has psychological difficulties. As discussed, no eligibility criteria were stipulated because we wanted to recruit a representative sample of parents engaged with the CAMHS. The sample thus comprised parents whose youth had been diagnosed with a range of psychopathologies, including comorbid developmental problems. Whilst youths' diagnostic information was reported, this study did not explicitly control for type of diagnosis. It is thus difficult to ascertain from these results whether participants' loss and grief was shaped by the nature of their child's difficulties. Indeed, it is possible (and perhaps likely) that different youth psychopathologies exert different impacts on parents. Similarly, parents' mental health status was assessed but not controlled for, which makes it difficult to discern whether participants' own psychological health impacted their adjustment to their child's condition.

Future research on parents' loss and grief in the context of their youth's mental illness should target various populations and the recruitment of fathers should be a priority. Longitudinal studies of parents' grieving would compliment cross sectional data and facilitate a better understanding of parents' grief process as time since diagnosis elapses. The course of parents' grieving could be examined via qualitative or quantitative methods. It is recommended that future studies investigate whether parents' loss and grief is determined by the nature of their youth's difficulties (e.g., diagnosis type, illness severity and duration) as well as their own prior or current psychopathology. Perceived social support, caregiving challenges and the attitudes of others were common themes in participants' narrative; as such, it may be useful to explore whether parents' grief is predicted by similar psychological constructs. Indeed, results of previous studies that sought to identify correlates of grief among families of a mentally ill adult relative have been inconsistent (see Richardson et al. 2011). Finally, the absence of evidence based support for parents adjusting to their child or adolescent's mental illness is alarming. Future studies should aim to develop, implement and evaluate programs of support for parents engaged with treatment services because their youth has psychological difficulties. The current study highlighted some possibilities for clinical intervention.

In conclusion, knowledge on loss, grief and familial mental illness is largely based on adult psychiatric patients and the experience of their ageing parents. The present study expands on this literature. We explored the loss and grief of parents and carers attending a CAMHS in relation to their child's difficulties, and found that their experience largely converges with the accounts of adult patients' families. It would also seem that constructs in the grief and bereavement literature have relevance for conceptualizing these parents' experience; notably, notions of ambiguous and nonfinite loss (Boss 1999; Bruce and Schultz 1992), chronic sorrow (Olshanksy 1962) and disenfranchised grief (Doka 1989, 2002). Exploring these parents' loss and grief allowed us to identify some therapeutic needs of parents accessing the CAMHS. More research is needed to better understand the course and determinants of parents' grieving over time. Such knowledge would facilitate the development, implementation and evaluation of evidence-based, grief support for youths' families.

Appendix

1. I'd really like to hear a little about (young person's name).
   Can you describe (young person's name) personality?
   What does (young person's name) mean to you?
   What is your relationship like with (young person's name)?
2. How did you come to learn that (young person's name) has a mental health condition?
   Are you able to talk through what happened?
3. Some parents have said that, before taking their child to see a psychologist or GP or another health worker, there was a period of time where they felt like something just wasn't right with their child. Perhaps it was the way their child behaved, or how their child got on at home or school, that first indicated that something may be going on. How about you, what was your experience like?
4. When you first suspected that (young person's name) may have a mental illness, can you recall how you felt?
   What kind of emotions did you experience at the time?
   What was that like for you?
   Can you tell me more about those feelings?
5. During that time, what kinds of things were running through your mind?
   What went through your head back then?
   Do you recall thinking about certain things?
6. When you were first told by a health professional (such as a psychologist or GP or social worker or psychiatrist) that (young person's name) has a mental health condition, what was that like for you?
   Are you able to share with me some of those feelings?
   Can you describe the emotions you felt?
   What went through your head at the time?
7. Some parents have said that when they were first told their child had a mental illness, they felt a sense of loss. Did you experience anything similar to this, when you first found about your child had a mental health condition?
8. Some mums and dads have said this loss was associated with great sadness or sorrow. Did you experience a similar feeling, or was your experience different?
9. Has (young person's name) received a specific mental illness diagnosis?
   [*If YES*]
   What is your understanding of this diagnosis?
   What does this diagnosis mean to you?
   How did learning of this diagnosis make you feel?
   Can you recall how you first reacted, when you were told (young person's name) has this illness?
10. When you first found out about (young person's name)'s mental health condition, how did you cope with those strong feelings and thoughts?
    How did you get on?
    How did you manage?
11. How do you currently feel about (young person's name)'s mental illness?
    How are things for you, now?
    How do you feel, talking to me about (his/her) condition?
    Can you describe some of the feelings you have, when thinking about your child?
12. Some parents describe a sadness in them, when talking or thinking about their child. I'm wondering if you've ever felt this way? Or is your experience different?
13. (Parent's name), would you say that you're grieving your child's condition?
    [*If YES*]
    What is that like for you?
    Can you tell me about that?
14. Have there been times when you've felt angry, or worried, or resentful, sad, or perhaps frustrated, when thinking about (young person's name)?
    [*If YES*]
    What is that like for you?

15. Are there certain things—such as events, memories, or perhaps certain times of the year—that bring up these feelings you have?
    [*If YES*]
    What sorts of things bring up those feelings?
16. Do you ever find yourself thinking back to the time when you first found out about (young person's name)'s mental health issues?
    [*If YES*]
    What do you think about?
    How does it make you feel?
17. How do you see (young person's name)'s future?
    What kind of hopes or dreams do you have for (young person's name)?
    Have these hopes and dreams changed since he/she developed this condition?
18. How do you feel when thinking about his/her future?
19. What does (young person's name)'s mental health condition mean to you?
    What does his/her condition mean for your hopes and dreams?
    What about the hopes and dreams of your family?
20. In what ways has (young person's name)'s mental health condition affected your life?
21. As a parent of a young person with mental health issues, how do you cope or manage?
    How have you been getting on lately?
    Are there things you do to feel better or cope with strong emotions?
22. Are there people in your life you can turn to?
    Can you talk about your experiences with someone?
23. How do you feel about talking to others (family, friends, relatives, neighbors, colleagues, health professionals, for example) about (young person's) mental health condition?
    Do you feel comfortable talking about this with others?
    Are there obstacles that stop you from, or make you feel hesitant about, talking to others about your experiences?
24. What, if any, have been some challenges for *you*, as a parent of a young person with a mental health condition?
25. Would you say that (young person's name)'s mental health condition has impacted on your family's day to day life?
26. If you were to offer advice to parents in a similar situation to you, what might you tell them?
27. How would you describe your experiences with the mental health services you've accessed regarding (young person's name)'s mental illness?
28. Finally, if support was available for parents who were having some difficulty coping with, or adjusting to, their child mental health issues, what kind of support do you think would be helpful? By "support", I mean things like counseling or therapy.
    What do you think parents need in this situation?
29. Thank you again for sharing your experiences with me, your comments have been very helpful. That covers the things I wanted to ask you today. Is there anything you would like to add? Any comments you'd like to make? Thanks very much, I really appreciate your time.

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