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CERI R. JONES BA Hons

AN EXPLORATION INTO PARENTS' EXPERIENCES OF  
ADOLESCENT MENTAL HEALTH DIFFICULTIES

Section A: A literature review of the impact of adolescent  
mental health difficulties on parents

Word Count

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Section B: A narrative study exploring how parents make  
sense of adolescent mental health difficulties

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## Summary of the MRP

**Section A** critically reviews the qualitative literature relating to parents' experiences of adolescent mental health difficulties. It synthesises key themes that emerge from the research to date with theoretical literature from related fields. Both clinical and research implications are outlined and future areas for research are identified.

**Section B** is a narrative study that explores the way in which parents make sense of their adolescent's mental health difficulties. Results suggest that many parents have difficulty in finding meaning in their situation, which may leave them vulnerable to experiences of loss and grief. Implications for future research and for clinical practice are discussed in light of these findings.

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**MAJOR RESEARCH PROJECT**  
SECTION A: LITERATURE REVIEW

A literature review of the impact of adolescent  
mental health difficulties on parents

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## **Abstract**

There has been little research to date into the experiences of parents whose adolescent children experience mental health difficulties. Research into parents whose adult children have mental health difficulties suggest that they experience feelings of grief and loss. However whether parents of younger children experience similar feelings has yet to be explored. A systematic literature search was carried out to identify relevant papers and a total of 16 qualitative studies were included in this review. These studies were critiqued in line with qualitative quality assurance criteria and were found to be widely lacking in rigour. Results however suggest that parents may experience a number of losses related to their child's difficulties. Implications for clinical practice are discussed in relation to relevant theoretical literature and ideas for future research are suggested that address the limitations of the current studies.

**Keywords:** Parent, Adolescent, Psychiatric, Impact, Loss

## **Introduction**

### **Historical Context**

Much of the literature pertaining to parents of children with mental health difficulties has traditionally related to the aetiology of childhood psychiatric disorders. During the early and mid 20<sup>th</sup> century, many of the attempts to understand the cause of childhood psychological distress came from the psychoanalytic field (Bateson, Jackson, Haley, & Weakland, 1956; Sullivan, 1927). These theories were widely held in high regard and posited that poor parenting may be the main or usual cause of childhood behavioural or emotional difficulties (Corrigan & Miller, 2004). Psychiatric services were subsequently built upon the assumption that parents may be causally responsible for their child's difficulties (Modrcin & Robison, 1991).

It has become increasingly accepted that a wide variety of factors can influence mental health, including biological, psychological and social factors. In fact, parenting was estimated to only account for between four and eight percent of childhood mental health difficulties in one study, and this is likely to be an over-estimate due to methodological limitations of the studies that have provided these calculations (McLeod, Weisz & Wood, 2007). One theory that has attracted significant attention is that there is a biological basis to mental health difficulties. It was initially hypothesised that such theories would reduce the blame directed at the parents of those diagnosed with a mental health disorder (Hinshaw, 2005). Whilst a genetic explanation may theoretically serve to reduce blame towards

parents (Phelan, 2005), family members who view it in this way experience increased levels of sadness, pessimism and psychological distress (Moses, 2011; Van der Sanden, Bos, Stutterheim, Pryor, & Kok, 2013).

Despite advances in understanding however, parents of those with mental health difficulties often report feeling blamed for their child's difficulties. Unfortunately, in addition to the general public sometimes holding parents responsible for causing their child's mental health problems (Corrigan & Miller, 2004), research has also demonstrated that parents often feel blamed or excluded by mental health professionals (Pejlert, 2001). Perhaps not surprisingly then, research has also found that parents frequently blame themselves for their child's mental health difficulties (Moses, 2010).

In summary, although theories about the causes of mental health have changed over time, parents still perceive significant levels of blame from a variety of sources.

### **The Impact of Having an Adult Child with Mental Health Difficulties**

Whilst there is a wealth of literature relating to the causes of childhood psychological distress, there is relatively little on the experiences of their parents (Angold et al, 1998). The majority of literature pertaining to parents' views in this field relates specifically to their levels of satisfaction with mental health services for their children (Gerten & Hensley, 2014). However the impact that having a child with mental health difficulties has on parents has received far less

attention (Harden, 2005).

Whilst research into the experiences of parents whose children develop mental health difficulties has been relatively limited, research into the impact of having a child with a learning disability, genetic disorder or developmental disability has been studied extensively (Douglas, 2014). Research into these parents has shown that they may often experience a grieving process for the loss of the “perfect child” they had originally anticipated having (Ellis, 1989). The onset of this grieving process for parents of disabled children is thought to typically occur when a child receives a diagnosis.

Research that has explored how parents are impacted by their offspring’s mental health difficulties has been relatively recent and has primarily focused on the experiences of those with adult children (Johansson, Anderzen-Carlsson, Ahlin & Andershed, 2010; Richardson, Cobham, McDermott & Murray, 2013). Research within this field has found that parents may experience multiple losses over the course of their child's mental health difficulties (Tuck et al, 1997). In line with research into parents of children with physical disabilities, a recent review of studies of parents with adult children found that a sense of loss was often first experienced when their child was given a psychiatric diagnosis (Richardson et al, 2011). Some parents described how their child had changed and no longer seemed to be the person they knew (Jones, 2004; Tuck, du Mont, Evans & Shupe, 1997). Additional losses related to parents’ hopes and expectations, which often had to be frequently reevaluated for the lives of their child, themselves and their family (Milliken & Northcott, 2003).

Across the literature relating to parents with adult children, the dominant themes are those of pervasive grief and loss. Other themes however have also been noted, including guilt and blame, tensions with mental health professionals and the fluctuating nature of hope (Ferriter & Huband, 2003; Johansson et al, 2010; Pejler, 2001; Tuck et al, 1997).

### **Relevant Theoretical Literature**

#### **Chronic sorrow.**

Olshansky (1962) was the first to propose that parents of disabled children may experience recurrent losses throughout their lives, in what he termed “chronic sorrow”. Although Olshansky provided no definition of this term, chronic sorrow was later defined as “pervasive sadness that is permanent, periodic, and potentially progressive” (Eakes, 1995, p.78). The most prominent feature of chronic sorrow is its ongoing and cyclical nature and as such it can often be seen in individuals who have long-term caregiving responsibilities (Harris & Gorman, 2011).

Although originating from observations of parents whose children had disabilities, chronic sorrow is the theory most drawn upon in the literature regarding parents of adults with mental health difficulties. Several studies have suggested that the ongoing and fluctuating nature of grief that parents of adult children with severe mental health difficulties report can be understood in this

way (Eakes', 1995; Johansson et al, 2010; Mohr & Regan-Kubinski, 2001; Pejler, 2001; Richardson et al, 2011).

Whilst chronic sorrow has been linked to parents of adult children with severe mental health difficulties, little is known about its relevancy to parents with younger offspring. It seems likely, however, that this theory may be less applicable to this group, given that the onset of mental health problems is likely to be relatively recent and as such the associated difficulties are unlikely to be chronic or cyclical at this stage. Richardson, Cobham, McDermott and Murray (2013) therefore proposed that two other theories, both originating from the bereavement literature, may be more applicable to parents of adolescents with mental health difficulties; disenfranchised grief (Doka, 1989) and ambiguous loss (Boss, 1999).

### **Disenfranchised grief.**

Doka's (1989) theory of disenfranchised grief referred to a range of grief experiences that are not, or cannot be, acknowledged by society. He proposed that one such instance of this was "when the persona of someone has changed so significantly, as a result of mental illness" (Doka, 1989, p.38). Despite applying his theory to those with mental health difficulties, the majority of studies to date have explored the alternative avenues of disenfranchised grief that he also outlined. The theory has been applied primarily to instances in which the griever, rather than the loss, is not recognised, such as children, the elderly and people with learning disabilities (Doka, 1999).



**Ambiguous loss.**

Boss (1999) first proposed the term ambiguous loss, of which there are said to be two types: physical and psychological. Physical ambiguous loss occurs when someone is psychologically present but physically absent, such as those who are missing. In contrast, psychological ambiguous loss refers to instances when someone is physically present but psychologically absent. Research into psychological ambiguous loss has taken place with family members of those who have been given diagnoses of Alzheimer's (Sanders & Constance, 2003), Autism Spectrum Disorders (O'Brien, 2007) and chronic physical illness (Boss & Couden, 2002). However, despite Boss (2006; 2011) noting chronic mental illness as another form of psychological absence, the relevance of this theory has not been applied to the relatives of those with mental health difficulties to date.

Both disenfranchised grief and ambiguous loss linked experiences of loss and grief to the changes that people witness in their loved ones due to mental health difficulties. However, these theories have rarely been cited in the literature on parents of those with mental health difficulties, with the focus instead being on the related construct of chronic sorrow. Remarkably however, the discourses used in these theories and in the studies outlined above are strikingly similar. Jones (2004) for example noted "the difficulty of adjusting to the loss of a person who has not actually gone away but is seen as if they are someone else" (p.40).

All three theories outlined above relate to instances in which the loss is a living or non-finite (Bruce & Schultz, 2002) one and as such is more likely to not be socially acknowledged. The prevalence of loss as a recurring theme in the mental

health research suggests that the applicability of these theories should be explored further.

## **Rationale**

Despite significant research into the parents of adults with mental health difficulties, there has been little exploration of the experiences of those with children and adolescents with these difficulties (Richardson, Cobham, Murray & McDermott, 2011). Research interest in parents with younger children has been relatively recent and as such there has yet to be a systematic review of this literature.

The lesser attention to parents of non-adult children is surprising, given that the onset of many mental health problems is most often thought to occur in adolescence (Jones, 2013). Approximately half of all psychiatric disorders begin by the mid-teens and by the mid-twenties this proportion reaches three-quarters (Kessler et al., 2007). Prevalence rates of psychiatric disorders are estimated to be roughly 20 percent in the adolescent population (Costello, Copeland & Angold, 2011).

Exploring the experiences of parents whose children are adolescents is important because the evidence from those with adult children suggests that this may often be when their grief first manifests (Richardson et al, 2011).

Furthermore, whilst researching the experiences of parents with adult children is important, it provides only a retrospective account of how parents experienced the early stages of recognising and coming to terms with their child's mental health difficulties. Exploring the experiences of those in "real time" (Richardson et al, 2011, p.40) may lead to a richer understanding of the initial stages of parents' possible grief processes. It has also been shown that parents play a crucial role in their adolescent child's recovery and so understanding and supporting their needs will ultimately enable them to better support their children.

In their review of the parents of adult children literature, Richardson et al (2011) made two recommendations for future research that the current review aims to meet. Firstly, that the experiences of parents with children or adolescents who experience mental health difficulties needs to be explored, and secondly, that studying the applicability of bereavement theories to this group should be a priority.

### **Research Aims**

The following review therefore explores the existing literature pertaining to parents' experiences of their adolescent child's mental health difficulties. Specific research questions that it aims to address are:

- How are parents impacted by adolescent mental health difficulties?
- Do parents of adolescents with mental health difficulties experience the same loss and grief that those with adult children do?

- If so, can theories pertinent to parents of adult children also help to explain the experiences of parents of adolescents?
- What areas still need further research?

## Methodology

### Search Strategy

Five online databases were searched: Ovid MEDLINE, PsycInfo, PubMed, ASSIA and Web of Science. The current literature was searched using the terms outlined in Table 1.

Table 1  
*Search Terms*

Terms related to parents		Terms related to adolescents		Terms related to mental health difficulties		Terms related to qualitative impact
parent*		adolescen*		psychiatric*		experience*
OR		OR		OR		OR
mother*	AND	you*	AND	mental*	AND	narrative*
OR		OR		OR		OR
father*		teen*		psycholog*		stories
OR				OR		OR
paternal				emotional*		interview*
OR				OR		OR
maternal				distress		qualitative*
OR				OR		OR
famil*				diagnos*		impact
OR				OR		OR
son*				depress*		meaning*
OR				OR		OR
daughter*				psycho*		sense
OR				OR		OR
child*				schizophreni*		report*
				OR		OR
				anx*		perception*

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OR eating disorder*	OR view*
OR	
personality disorder*	

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*Note.* \*=indicates truncation.

In order to identify whether additional papers of interest had been overlooked, the same search terms were also entered into Google Scholar and the references of all relevant articles were examined. These initial searches returned 237 articles, which were subsequently filtered out according to the following criteria.

### **Inclusion and Exclusion Criteria**

Papers were only included if they employed an empirical design, whereas meta-analyses, reviews, and conceptual or theoretical papers were excluded. Given that the present review was concerned with the meaning that parents make of their experiences, studies were required to have employed qualitative or mixed methodology. Studies that only collected quantitative measures were excluded. Although the inclusion of quantitative studies could have elicited additional information, such as the prevalence rates of grief symptoms in parents, the current review was concerned with gaining a deeper insight into parents' experiences as reported in their own language. Furthermore, quantitative measures of grief responses have yet to be validated with relatives of those with mental health difficulties (Richardson et al, 2011).

Papers whose samples did not primarily consist of parents were also excluded, as were those that did not primarily focus on mental health difficulties. Given

that co-occurring mental health difficulties are prevalent within adolescents with neurodevelopment disorders, samples that included parents of these children were included, but only in instances where they did not comprise the majority of the youth sample. In order to be included in this review, the sample must have focused on the parents of adolescents. The WHO (2014) age range of 10-19 years was employed for this search, meaning that the mean age of parents' children had to fall within this range. In cases where there was not enough information to calculate a mean age, then the majority of the youth sample had to fall within the 10-19 years range. Given the paucity of research into parents' experiences of adolescent mental health difficulties, no restriction was placed on publication dates.

A flow-chart of the exclusion process can be found in Figure 1, which resulted in a total of 16 papers. Two of these papers used the same sample but both were included in the review as the author focused on different aspects of parents experiences in each. Summaries of each study can be found in Table 2.

Figure 1  
*Exclusion process of review papers*

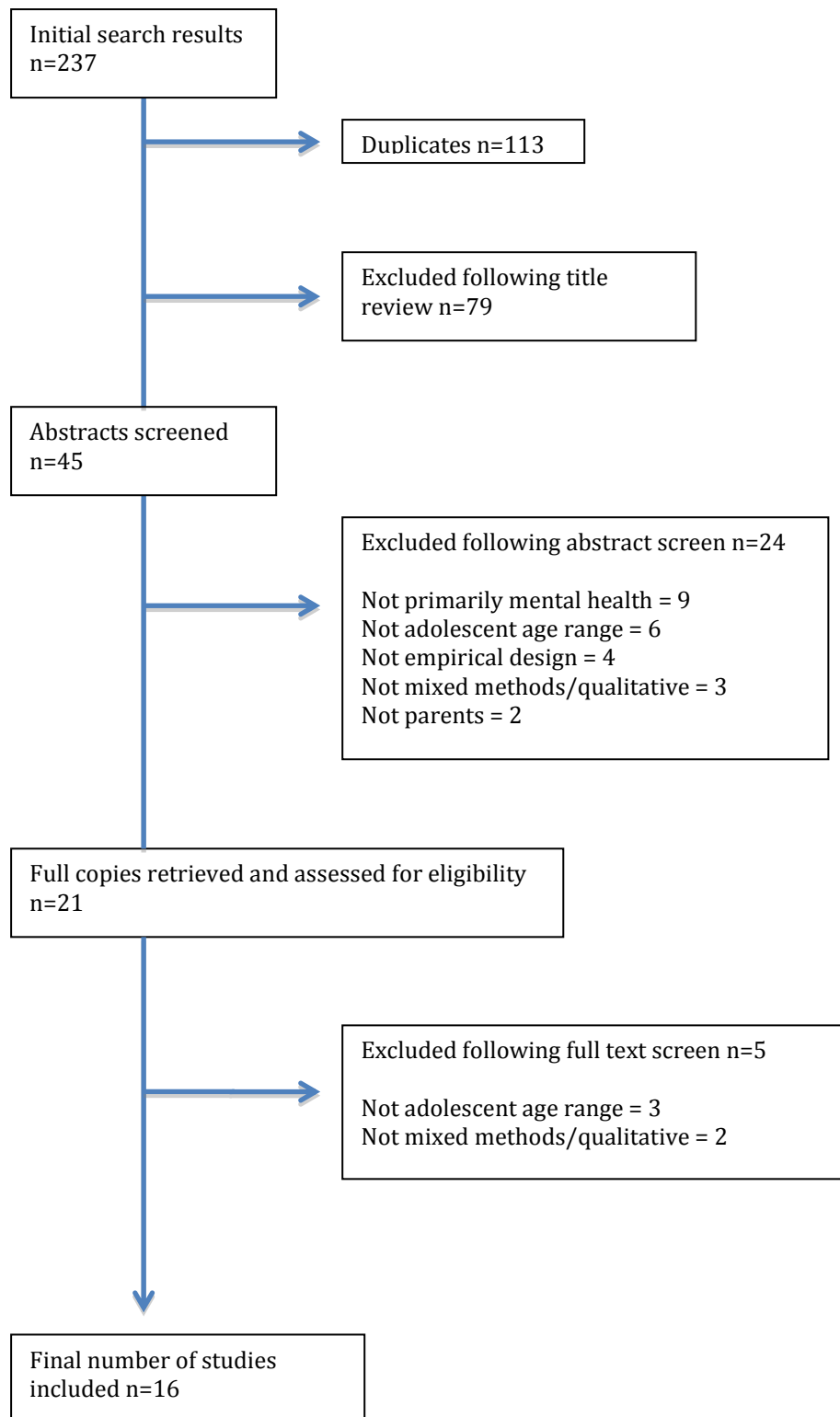


Table 2  
*A Summary of Each Study Included in the Review*

Author(s) & Year of Publication	Country	Parent sample	Adolescent sample age range & diagnoses	Data collection method	Area of exploration	Key findings or themes
Bezance & Holliday (2014)	UK	9 parents 9 mothers	13-16 Anorexia nervosa	Semi-structured interviews	Mothers' experiences of a home treatment team	Becoming enmeshed with their daughters, resulting in them losing a sense of their own identity and becoming isolated from others. Despair, exhaustion and helplessness, as well as a sense that their daughter had changed as a person. Difficulties accessing appropriate help and feeling excluded from their daughters' care once they did receive it. The



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need for containment and a renewed strength when this was received.

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Fear of the unknown – emotional apprehension due to uncertainty of what happens in services, therapeutic engagement – the importance of being listened to and developing good relationships with professionals, making services acceptable – issues of accessibility, session tolerances and suggestions for development of child-centered services.

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Bone, O'Reilly, Karim & Vostanis (2014)

UK

14 parents  
12 mothers, 2 fathers

8-12  
GAD, mood disorder, phobia, adjustment reaction, bereavement, behavioural/oppositional difficulties, ADHD, ASD, attachment difficulties.

Semi-structured interviews

Parents' experiences of child outpatient mental health services

Geraghty, McCann, King & Eichmann (2011)	Australia	50 families 41 mothers/both parents– did not distinguish between the two, 5 fathers, 7 grandparents, 3 siblings	Not stated but service covers 5-17 year olds Diagnoses not stated. 'Acute mental health problems' cited as reason for psychiatric inpatient admissions	Written summaries of informal contacts	How parents utilise a peer support service at a mental health unit	Experience of service provision, emotions and feelings associated with the admission, need for information and coping with challenges.
Grob & Edinburg (1972)	US	84 parents 47 mothers, 37 fathers	13-19 Personality disorder, schizophrenia, 'severe neuroses', 'organic syndromes'	Semi-structured interviews	Parents' reactions to their adolescent child's psychiatric hospitalisation	Parental guilt, social stigma, feeling excluded from meaningful participation, resentment at relinquishing authority, the importance of communication with parents, the effect of hospitalisation on reintegration into community, frequently changing staff, financial hardship resulting from

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admission, emphasis on clinical psychiatry over after-care and rehabilitation.

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Harden (2005a)*	UK	25 parents 18 mothers, 7 fathers	13-16 OCD, bipolar disorder, schizophrenia, depression, anorexia nervosa	Semi-structured interviews	Parents' experiences of living with a young person with mental health difficulties	Reconstructing the past: searching for clues as to when and why problems had began, lack of knowledge, reliance on professionals, frustrations with the lack of clear answers or definite diagnoses, causal responsibility and guilt. Reconstructing the present: responsibility to cope with the situation, conflict around division of care between parents and
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						professionals. Reconstructing the future: concerns about their child's future, no end to direct parenting.
Harden (2005b)*	UK	25 parents 18 mothers, 7 fathers	13-16 OCD, bipolar disorder, schizophrenia, depression, anorexia nervosa	Semi- structured, in- depth interviews	Experiences of parents of children with mental health diagnoses	Parent Deskillling: not being listened to by the medical profession; helpless parenting; being excluded from care; parental causal responsibility. Parent Reskilling: critiquing psychiatric knowledge and practice; acquiring knowledge; renegotiating the parental caregiving role.
Jivanjee & Kruzich	US	18 family members	17-24 Bipolar disorder, depression, learning	Focus groups	Parents' experiences of	Positive experiences:

(2011)		14 mothers, 2 fathers, 1 aunt, 1 grandmother	disabilities, ADHD, behavioural disorder, OCD, PTSD		using mental health services and informal sources of support	family and peer support; compassionate, well trained and responsive to needs. Negative experiences: ineffective and unhelpful staff, lack of relevant services, loss of eligibility for services at 18. Ideal support: families, peer support, leadership development groups, accessible and appropriate services and responsive, compassionate providers.
Jivanjee, Kruzich & Gordon (2009)	US	42 family members 40 female, 2 male Family members with parenting	16-24 Depression, ADHD, PTSD, anxiety, ODD, learning disabilities, OCD	Focus groups	Family members' experiences of supporting transition-age youth in the	Opportunities to achieve goals and gain a sense of accomplishment, peer

responsibilities  
but did not define  
their family roles

community

relationships, lack  
of preparedness  
for adult life,  
difficulties  
forming  
relationships,  
stigmatizing  
attitudes, lack of  
community  
resources,  
strength-  
orientated  
services and  
opportunities for  
skill development,  
supportive  
mentoring  
relationships

Mohr (2000) US

40 parents  
25 mothers, 15  
fathers

3-18 at time of admission  
MDD, ADHD, atypical psychosis, substance  
abuse, OCD

Unstructured,  
in-depth  
interviews

Parents'  
experiences of their  
child being  
admitted into a  
psychiatric hospital

Feeling excluded,  
the pain of being  
isolated from  
their children,  
feeling  
marginalized,  
abnormalised and  
'insanitised',  
displaced in the  
child's life, feeling  
bewildered by the

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jargon, feeling powerless and coerced, the importance of developing interventions that employ competence and partnership.

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Alternative: external life circumstances, normal teenage behavior, child's behavior is intentional and can be controlled. Uncertain: a struggle to make sense of their child's difficulties, difficulty making sense when problems fluctuate, unreliable diagnoses, the desire to avoid thinking of their

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Moses (2011)	US	68 parents 60 mothers, 8 fathers 81% biological parents, 9% adoptive, 10% kinship legal guardians	12-18 Depression, conduct disorder, bipolar, PTSD, mood disorder, anxiety, OCD, ODD, substance abuse/dependence, reactive attachment disorder
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Semi-structured interviews

Parents' conceptualisations of mental health problems

child's problems in negative or culturally inappropriate ways. Psychiatric: mental illness, associated with increased duration and severity of difficulties.

Oldershaw, Richards, Simic & Schmidt (2008)	UK	12 parents 9 mothers, 2 fathers, 1 grandmother	13-18 Diagnoses not stated. 'Self-harm' cited as reason for community mental health services referral	Semi-structured interviews	Parents' perspectives of repeated self-harm	The process of discovery, making sense of self-harm, psychological impact of self-harm on parents, effect of self-harm on parenting and family
Puotiniemi & Kyngäs (2004)	Finland	1 mother	16 Diagnoses not stated. 'Suicidal behavior' cited as reason for psychiatric hospital admissions	Unstructured, in-depth interviews	Everyday coping demands and strategies for a mother and her daughter	Coping demands for mother: managing daughter's aggressive behaviour, worries about



						daughter's unstable mental health and future, concerned about interpersonal relationships within the family, developing somatic diseases. Mother's coping strategies: creative activities and social support.
Richardson, Cobham, McDermott & Murray (2013)	Australia	15 parents 11 mothers, 3 fathers, 1 grandfather	8-18 Separation anxiety disorder, OCD, GAD, anxiety disorder, adjustment disorder, phobia, anorexia nervosa, recurrent depressive disorder, dysthymia, elective mutism, self-harm behavior, language disorder, Asperger's syndrome, ODD, 'disturbance of activity and attention', 'childhood disorder of social functioning'	Structured interviews	Parents' loss and grief responses to having a child with mental health difficulties	Parents' narratives of finding out, profound and pervasive loss, complex grief, waning support, the challenges of caregiving and a call for assistance.
Thomson et al (2014)	UK	8 parents 7 mothers, 1 father	11-18 Anorexia nervosa	Semi-structured interviews	Parents' recognition and help-seeking for their child's eating disorder	Normalisation of early changes and observations, ambivalence and ambiguity about

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the meaning of these changes, decision point for help-seeking and the nature of family relationships.

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Accessing services: not having initial concerns recognised, the shock of a diagnosis, lack of appropriate service provision. Attitudes towards psychosocial interventions: appreciation of family therapy but sense that the adolescent did not benefit from this, the desire to have some sessions without the adolescent, too much emphasis

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Tierney (2005)	UK	13 parents 8 mothers, 5 fathers	14-19 Anorexia nervosa	Semi-structured interviews
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Experiences of parents with a child who has received treatment for an eating disorder

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on physical rather than mental progress.  
Encounters with professionals: lack of feedback from professionals, lack of communication between multiple professionals involved, professionals being too rigid in their conceptualization of behavior as a symptom of mental health problem, extremely grateful to professionals perceived to be on their side.  
Perceived progress: uncertainty regarding course of the condition, frustration with

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lack of perceived progress, anguish of relapses.

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We didn't see it coming: lack of mental health knowledge, self-blame, searching for how and why psychosis began, embarrassment and regret about not identifying it sooner.  
 Hopelessness and helplessness: fearful of the recovery process and feeling ill-equipped in supporting the adolescent in the future.

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Ward & Gwinner (2014)

Australia

10 parents  
6 mothers, 4 fathers

17-20  
Early psychosis

Open-ended questionnaires

Parents' experiences of their child's admission to an early psychosis inpatient unit

*Note.* \*=used same sample.

Table 3

*A summary of quality assurance checks completed for each study*

Author(s) & Year of Publication	More than one researcher contributed to analysis	Attention to negative cases	Respondent validation	Type of qualitative analysis stated	Evidence of researcher reflexivity
Bezance & Holliday (2014)	Yes	No	No	No	Yes
Bone, O'Reilly, Karim & Vostanis (2014)	Yes	No	No	Yes	No
Geraghty, McCann, King & Eichmann (2011)	Yes	Yes	No	Yes	No
Grob & Edinburg (1972)	No	No	No	No	No
Harden (2005a)	No	Yes	No	Yes	Yes
Harden (2005b)	No	Yes	No	Yes	Yes
Jivanjee & Kruzich (2011)	Yes	No	No	Yes	No
Jivanjee, Kruzich & Gordon (2009)	No	No	No	No	No

Mohr (2000)	Yes	Yes	Yes	Yes	Yes
Moses (2011)	Yes	No	No	Yes	No
Oldershaw, Richards, Simic & Schmidt (2008)	Yes	No	Yes	Yes	No
Puotiniemi & Kyngäs (2004)	No	N/A Case study	No	Yes	No
Richardson, Cobham, McDermott & Murray (2013)	Yes	No	No	Yes	No
Thomson et al (2014)	Yes	No	No	Yes	No
Tierney (2005)	Yes	No	Yes	No	Yes
Ward & Gwinner (2014)	Yes	No	Yes	Yes	No

### **Quality of the Literature**

Due to the paucity of research within the field, the quality of papers did not determine their inclusion or exclusion within the review. However, all of the studies were critically reviewed in line with quality assessment guidelines for qualitative research (Mays & Pope, 2000). A summary of the results of this process is depicted in Table 3.

As Table 3 shows, the quality of the included papers, as appraised using Mays and Pope's (2000) guidelines for qualitative research, was generally fairly low, with only one of the 16 papers meeting all of the suggested methods for maximizing validity (Mohr, 2000).

Issues relating to transparency are crucial within qualitative research, as researchers are acknowledged to influence and shape their findings based on their own assumptions and motivations (Yardley, 2000). For this reason it is considered very important to leave an audit trail of the entire research process, to demonstrate to readers how the researcher's beliefs and thoughts altered over the course of the study (Rodgers & Cowles, 1993). Very few of the papers included in this review provided examples of researcher notes or diary entries. Unfortunately reflections from researchers regarding their own positions in relation to their data were also rarely included. Walsh and Downe (2006) noted that this important aspect of the qualitative research process is often excluded from finalized manuscripts due to the word limits imposed by journals.

## **Results**

All of the studies made reference to the psychological impact of having a child with mental health difficulties. A range of difficult emotions were expressed, including sadness, grief, disappointment, guilt, loss, despair, exhaustion, fear and anxiety. However only one study made explicit reference to the grief model.

### **Loss of their Child**

In line with the literature from parents of older offspring, some parents spoke about how mental health difficulties had resulted in the loss of their “real child” (Richardson et al, 2013, p. 726). Although behaviour changes are part of normative adolescent development, parents in some studies spoke of them as more permanent personality changes (Bezance & Holliday, 2014; Harden, 2005a). Others however attributed their child’s difficulties to transient and ‘normal’ teenage behaviour (Moses, 2011; Thomson et al, 2014).

### **An Uncertain Future**

Parents voiced concern about the future both for their children and for themselves (Bezance & Holliday, 2014). As parents of adult children have reported, these parents were also worried that their child may encounter difficulties in areas that they had previously assumed the adolescent would succeed in, such as gaining employment and having relationships (Harden, 2005a; Moses, 2011). Their uncertainty about the future course of their child’s



mental health difficulties seemed to exacerbate these concerns (Tierney, 2005).

### **Loss of the Typical Parenting Trajectory**

The role of parenting typically develops over the course of a child's life, so that there is a gradual separation between the parent and child as they begin to enter into adulthood. However this expected trajectory is altered when mental health difficulties develop during this transition period (Milliken & Northcott, 2003). Several papers noted that the role of parenting is extended (Jivanjee et al, 2009), with Harden (2005a) likening it to a reversal of the separation process, in which the child becomes "more 'childlike' and more dependent on their parents" (p. 361).

In one sense parents reported feeling a sense of responsibility for their children well beyond the timeframe they expected to. However another theme that emerged from the literature was the discrepancy between how parents and psychiatric services view parental responsibility. Several articles pointed to the difficulty that parents encounter with the legal system surrounding the transition from child to adult services. In particular, laws regarding confidentiality often meant that information was withheld from parents when the child was deemed to be of an adult age in the eyes of the law. Yet parents frequently reported feeling as though their child may be less able to make appropriate decisions for themselves than their peers due to their mental health difficulties (Jivanjee, Kruzich & Gordon, 2009). As such, the age threshold used by clinical services for parental responsibility was felt by some parents to be arbitrary and some parents suggested that their child's capacity to consent

should instead be considered within the context of their difficulties (Harden, 2005b).

### **Everyday Impact**

Several studies mention what appear on the surface to be practical consequences on the day-to-day lives of parents. Some parents had stopped working, changed jobs, or had significant time off in order to care for their child (Geraghty et al., 2011; Richardson et al., 2013). Parents in two studies used metaphors of looking after a baby to reflect the all-consuming nature of their child's difficulties (Bezance & Holliday, 2014; Oldershaw et al., 2008). Researchers concluded that the level of input required had left parents feeling exhausted and drained of both physical and emotional energy (Harden, 2005a; Bezance & Holliday, 2014).

Looking beyond the practical aspects, closer inspection revealed that parents seemed to be voicing their loss of independence and time to themselves. Indeed, one study noted that parents described losing their own identity amongst their child's difficulties (Richardson et al., 2013).

Although a financial impact was noted in several studies, these tended to come from studies that were carried out in the United States. Parents in these studies cited issues that related specifically to the American system, such as complications regarding eligibility to claim for the child's care on health insurance (Jivanjee & Kruzich, 2011). A factor relevant perhaps to parents in a range of countries however was the acknowledgement that families who required specialist services often spent significant sums of money on travel expenses as these services are scarce by their very nature (Geraghty et al., 2011).

In instances where parents had altered their work situations to meet their adolescent's mental health needs, this often impacted negatively on the family finances.

### **Family Impact**

Parents frequently reported that their everyday lives and family routines were disrupted as a result of their adolescent's difficulties. For some parents, the level of care required to care for their child had widespread consequences for the family as a whole. Parents often adapted their behaviour as a consequence of the adolescent's mental health difficulties, with some studies quoting parents as saying they were 'walking on eggshells' (Oldershaw et al., 2008; Thomson et al., 2014). Tensions within the spousal relationship were also noted in some papers due to parents having little time for each other (Puotiniemi & Kyngäs, 2004) or having different levels of input with regards to caring for their child (Harden, 2005a). Some parents also noted that their families were less able to engage in leisure activities outside of the home together (Richardson et al., 2013).

As well as worrying about their adolescent's wellbeing, some parents were concerned about the impact on their other children (Geraghty et al., 2011). For these parents a particular source of stress was trying to meet each child's needs, particularly as the adolescent with mental health difficulties often required more of their attention (Oldershaw et al., 2008; Puotiniemi & Kyngäs, 2004; Richardson et al., 2013). In some instances parents feared that their other children had 'bottled things up' and in others siblings expressed high levels of resentment towards the adolescent (Tierney, 2005). Some parents worried that

their other children were fearful that they might develop mental health difficulties themselves (Geraghty et al., 2011). Other studies noted that siblings could experience feelings of shame due to the social stigma attached to mental health difficulties (Puotiniemi & Kyngäs, 2004).

Although the majority of the studies reported negative impacts on relationships within the family, a few noted that the adolescent's mental health difficulties actually brought families closer together. This predominately related to a stronger bond between parents and the adolescent with mental health difficulties (Oldershaw et al., 2008; Tierney, 2005), although one study noted that some parents reported that the family as a whole had become more open with one another (Thomson et al., 2014).

### **Stigma**

Research suggests that social support from friends, family and peers is a particularly important aspect of coping for this population (Puotiniemi & Kyngäs, 2004). Yet parents in some studies reported increased social isolation as a result of stigma, blame and their extended caring responsibilities (Bezance & Holliday, 2014; Geraghty et al., 2011; Richardson et al., 2013).

Stigma also emerged as a common theme across the studies which explored parental help seeking. Several studies noted that parents had refrained from telling their friends about their child's difficulties (Grob & Edinburg, 1972; Jivanjee et al., 2009). Some parents voiced a fear of rejection from the wider community (Geraghty et al, 2011; Thomson et al, 2014), whilst others described

protecting their child from possible stigma by not telling their own friends about their child's difficulties (Harden, 2005).

The theme of blame appears repeatedly within the literature, however it is difficult to ascertain from parents' reports whether they are referring to actual or perceived blame. Furthermore, researchers have tended to create interview schedules that specifically ask parents for their views on causation or responsibility for their child's difficulties and more directly on their experiences of guilt, blame or stigma (Harden, 2005; Richardson et al, 2013). It is possible therefore that the way in which interview schedules were constructed may have prompted parents to talk about these topics. The extent to which such themes would emerge in parents' accounts without prompting from researchers remains unclear at present.

### **Difficulty Accessing Services**

A prominent theme across studies was the difficulty parents encountered when initially trying to access mental health services. This seemed to be a universal experience, regardless of the country in which the research was carried out. Barriers to accessing mental health services were often encountered when parents first sought help through primary care services. As well as feeling that their concerns were not taken seriously initially (Harden, 2005b; Thomson et al., 2014), some parents also reported that they felt blamed by professionals (Richardson et al., 2013). Other reasons for the difficulty in accessing adolescent mental health services included stringent eligibility criteria, a lack of resources and a lack of follow-up between staff members (Bone et al., 2014; Jivanjee &

Kruzich, 2011). Studies unanimously referred to this struggle, with many parents describing how they had to fight for their child to be seen.

### **Communication with Professionals**

Once they had been successful at gaining access to mental health services, many parents were disappointed by the lack of communication from the staff (Bone et al., 2014). Some felt that they should have received more feedback about the care that their child was receiving (Tierney, 2005), an issue that was exacerbated when adolescents reached 18 years of age. Parents whose children had been hospitalised often described feeling displaced and estranged in their child's life, as if they had lost their caregiving role to professionals (Harden, 2005b; Mohr, 2000; Ward & Gwinner, 2014). However, even parents involved in community mental health services sometimes described feeling excluded.

The most prominent theme however seemed to be that parents wanted more information about their child's illness and advice on how best they could manage it (Bezance & Holliday, 2014; Geraghty et al., 2011; Grob & Edinburg, 1972; Harden, 2005a). The lack of forthcoming information left parents feeling helpless, powerless and unable to fix the problem (Harden, 2005b; Mohr, 2000; Oldershaw et al., 2008; Thomson et al., 2014). The fact that their child's mental health difficulties had come as a shock to them left them fearful that they would not be able to prevent future relapses (Ward & Gwinner, 2014). Parents often searched for answers to explain why their child had become unwell and some expressed that they wished they had sought help sooner (Oldershaw et al., 2008;

Thomson et al., 2014; Ward & Gwinner, 2014).

Parents also wanted more recognition, containment and validation of their own needs (Bezance & Holliday, 2014; Harden, 2005b; Grob & Edinburg, 1972). Mental health professionals not addressing parents' grief, or mistaking it for pathological behaviour, has been previously noted (MacGregor, 1994). The collective findings suggested that a particularly important factor for parents was the extent to which they felt listened to by professionals and this was correlated with higher levels of parental satisfaction with services regardless of the overall outcome for their child (Grob & Edinburg, 1972). On the occasions when parents reported positive experiences of services, they tended to express gratitude towards one or two specific individuals, rather than the collective team (Geraghty et al., 2011; Tierney, 2005). This may provide some preliminary evidence that parents are better able to get their needs met through a direct relationship with a named clinician.

## **Discussion**

Many of the themes reported by parents of adolescents reflected those voiced by parents with older children. Both groups reported losses in relation to who their child was before they became unwell and what their future may now look like. However although parents expressed a range of difficult emotions, these were not described as being pervasive in nature. As expected therefore, chronic sorrow, the theory most often attributed to parents of adult children, appears

less applicable to this group.

Only one of the reviewed studies cited the grief model, yet it is possible that theories of grief and loss may help to explain the social isolation that parents described. Using Doka's (1989) theory of disenfranchised grief, it could be argued that the stigma of mental health which still prevails in today's society is likely to make it more difficult for it to be acknowledged socially. In addition to stigma contributing to social isolation, Boss (2007) also suggested that people do not know how to comfort relatives of people with mental health difficulties due to the ambiguity of their loss.

The reports of feeling excluded and unrecognised as parents concur with Doka's (1989) notion of disenfranchised grief. A particularly concerning finding is how little appears to have changed with regards to this. Despite one of the papers being over 40 years old (Grob & Edinburg, 1972), it is striking how many of the themes highlighted in the earlier paper still remain prominent for today's parents. It is possible that parents' needs may in part go unacknowledged due to the dominance of the medical model within psychiatric services, which tends to focus on the individual. Whether it is in adult or child services, the person presenting with mental health difficulties is considered to be the client and as such the interventions are focused primarily on their needs, perhaps at the expense of acknowledging the needs of their family. Systemic and family therapies however attempt to consider the needs of both the client and their wider network and are typically more widely offered within mental health services for children and adolescents than those for adults.



It is likely that the depth of parents' despair is not fully recognised at present (Attig, 2004). Indeed, as Pejler (2001) pointed out, there is a great deal of information regarding the challenges of caring for a child with mental health difficulties, but there is much less emphasis on the *meaning* of these difficulties for families. This may help to explain why, despite the increased liaison between parents and professionals within adolescent mental health services, parents often seem to feel unheard.

Uncertainty was a theme that seemed to run across a number of parental concerns and it is likely that the theory of ambiguous loss (Boss, 1989) would be a helpful starting point for understanding how to support parents with this. This theory posits that the ambiguity of the loss prevents closure and effectively freezes the grief process. However, Boss (1989) argues that rather than attempting to achieve closure, grievors must instead learn how to accept the ambiguity.

Whilst many of the themes from these studies bear resemblance to the literature on parents of adult children, several unique challenges for parents of this age group were also voiced. Given the hormonal and behavioural fluctuations known to characterise adolescence, an issue pertinent to this population is the difficulty parents may have in determining whether their child's behaviour could be considered a 'normal' teenage presentation or is instead symptomatic of a mental health problem (Moses, 2011). As well as impeding the recognition and help-seeking stages, this dilemma also left parents feeling uncertain about the

future for their family. Boss' (1989) theory of ambiguous loss provides clinicians with a potentially helpful way of conceptualising this experience. In the same way that it is ambiguous as to whether a missing person will be found or not, so too may there be significant ambiguity for parents as to whether the change is a longstanding or temporary one related to normative adolescent changes. Parents varied in the degree to which they perceived the permanency of their child's difficulties and it will be important therefore for professionals to tailor their support accordingly.

The fact that adolescence is expected to coincide with an increase in independence also created further complications for parents. Although young people were sometimes viewed by services as being of an age where they can be responsible for making decisions about their own care, parents felt they required more parental assistance with this than most adolescents would. The expected individuation-separation was disrupted for both parents and their children, particularly when inpatient services were required. Furthermore, parents of adolescents typically expect an increase in their own sense of freedom as their child develops their own independence (Milliken & Northcott, 2003). The loss of independence that some parents referred to may therefore be particularly challenging for this group.

Another key difference between parents of adult and adolescent children is that whilst parents are likely to facilitate access to mental health services, people who develop mental health difficulties in adulthood are more likely to seek a referral to adult services independently. For this reason, barriers that parents experience

towards help-seeking are worthy of further exploration in parents of younger children. As well as extensive difficulties accessing services, stigma was often perceived to delay parents seeking help, as parents worried about what other people would think of them and their family.

The theme of stigma seemed more prevalent in the studies included in the current review than in studies of parents of adult children. It is possible that the prevalence of stigma within the studies reviewed here is linked to the blame that parents encountered, because when parenting is viewed as the primary causal factor, stigmatising attitudes towards family members increases (Hinshaw, 2005). It may be that people hold less parent-blaming attributions towards adults with mental health difficulties, instead blaming the individual by, for example, viewing lifestyle choices such as heavy drug use as the cause. Or perhaps parents are simply further removed from blame as they become less involved in their child's mental health care.

## **Implications**

### **Implications for Practice**

Whilst Olshansky's (1962) concept of chronic sorrow has been widely referred to in the literature pertaining to parents whose adult children have mental health difficulties, the theory falls short of providing suggestions for therapeutic involvement. It was intended to encourage clinicians to view these emotional

responses as normal and in this sense it was hoped that this would lead to validation for parents (Gordon, 2009). However the findings from this review suggest that some parents continue to feel unsupported by professionals.

Possible solutions however may lie within the theoretical literature outlined in this review. By its very definition chronic sorrow is considered to be pervasive and ongoing, which leaves little room for hope and positive change. A similar critique has been made of disenfranchised grief by Attig (2004), who argued that the emphasis on acknowledging parents' suffering risks neglecting the equal need to help them move forwards. Both Attig (2004) and Boss (2006) suggest that in order to build parents' resilience, they must be supported in finding new ways of making sense of their experiences.

It is argued, therefore, that the theory of ambiguous loss, which does make explicit theory-practice links, could provide clinicians with possible avenues of intervention for parents. Practical suggestions for helping parents to find meaning in the ambiguity have been provided, including the use of narrative, dialectical and systemic therapies (Boss, 2006). These therapeutic approaches are also more socially based, drawing on strengths within the family as a whole.

Mental health services aimed at children and adolescents will need to find ways of ensuring that parents have the time and space to receive this support. The implication that parents particularly value having an individual they can liaise with provides some indication that a role similar to that of a key worker for clients may also be particularly beneficial for parents. Another possibility is the

inclusion of peer support services. Only two studies made reference to the provision of peer-led support for parents (Geraghty et al., 2011; Jivanjee & Kruzich, 2011). However both reported consistently positive experiences of these services. This compliments research into family members of adult children, which has found that peer support programs can increase self-reported coping and empowerment (Dixon et al, 2011) and reduce caregiver burden (Cook, Heller & Pickett-Schenk, 1999). Together these studies provide preliminary evidence that peer support should be further investigated as a viable intervention for parents of adolescents with mental health difficulties. Whilst there has yet to be an exploration of the aspects of these services that parents benefit from, it is likely that they meet some of the needs outlined above regarding feeling listened to and contained. Unlike professionals within mental health services for children and young people, whose task is primarily to take care of the adolescent, peer supporters are solely there to address the needs of parents, something that at present is missing in the overwhelming majority of child mental health services within the UK.

### **Implications for Research**

Research into parents of adult children with mental health difficulties has demonstrated the high prevalence of chronic sorrow in this population (Eakes, 1995). Retrospective reports from these parents suggest that their process of grieving often begins when their adult child is in their teenage years (Richardson et al, 2011). The research into parents of adolescents presenting with mental health difficulties reviewed here implies that this grief may first be experienced as an ambiguous loss. Of course for some adolescents, their mental health

difficulties will not continue into adulthood and as such their parents are unlikely to develop chronic sorrow. However when considered together, the findings from the literature on parents of adult and adolescent children with mental health difficulties provides some support for Boss, Roos and Harris' (2011) claim that "situations of ambiguous loss may lead to chronic sorrow" (p.166). Given that parents in these samples did not display pervasive sadness, it may be possible that providing them with the support that they need at the earliest opportunity may prevent the development of chronic sorrow. To test this hypothesis, future research could employ follow-up methodologies to assess the longer-term outcomes of providing parental support when families are first seen by child mental health services. One possible design for this type of study could be a longitudinal randomised control trial to determine whether interventions aimed at resolving ambiguous loss mediate parents' grief severity in those whose children go on to develop severe mental health difficulties in adulthood.

Although the literature reviewed in this paper provides preliminary support for Richardson et al's (2011) suggestion that the theories of disenfranchised grief and ambiguous loss could be helpful ways to conceptualise parents' experiences of their adolescent child's mental health difficulties, no study to date has tested this hypothesis directly. Future research would therefore benefit from specifically aiming to assess the applicability of loss and grief theories to the unique needs of this particular group. A useful first step would therefore be to provide concrete evidence that parents of adolescents currently experiencing mental health difficulties report current feelings of ambiguous loss, as opposed

to relying on retrospective accounts from parents of older children or inferring it from studies that have not directly explored this.

Many of Boss' (2006) suggestions for therapeutic input for resolving ambiguous loss relate to the ability to help individuals find meaning in the ambiguity.

Similarly, research in the bereavement field has demonstrated that meaning making is the strongest predictor of decreased parental distress following the loss of a child (Keesee, Currier & Neimeyer, 2008). Future research would therefore benefit from exploring *how* parents do or do not make sense of their child's mental health difficulties. Flesner (2013) summarised this well when she noted:

In order to develop effective meaning making interventions geared toward certain bereaved populations it is important for us to explore and understand which aspects of the meaning making process are unique to/most important for certain groups and are most helpful in moving them toward experiencing less acute, intense symptoms of grief and more ability to engage in their current life in meaningful ways. (p.11)

In order to develop a richer understanding of the ways in which parents of children with mental health difficulties engage in meaning making, additional methodologies could be employed beyond those used to date. Given that narrative analysis aims to illuminate the process of meaning making, this methodology may provide further insights into the experiences of parents whose children have mental health difficulties.

One of the ways in which individuals are thought to engage in meaning making is through the process of finding benefits or “silver linings” to the loss (Holland, Currier & Neimeyer, 2006). Boss (2006) has also highlighted the importance of identifying positive meanings of ambiguous loss. However the literature relating to parents’ of children with mental health difficulties has been largely problem saturated to date and there has been relatively little exploration of parents’ strengths and resilience. Research into parents’ strengths would not only help inform interventions aimed at supporting them but would also provide an alternative discourse for these parents. Although traditional theories of parental causation have diminished (Hinshaw, 2005), parents still report self-blame and guilt and so research would benefit from finding alternative, more helpful narratives that parents may be able to draw on.

In this relatively new field of research there are a number of other avenues that future investigators could take. For example, research could also explore whether conceptualising parents’ responses to their child’s mental health difficulties as loss has an impact on mental health professionals’ attributions. Although a little outdated now, MacGregor (1994) suggested that professionals often misinterpret parents’ responses to their child’s mental health difficulties as pathological. It would be interesting therefore to test whether professionals who conceptualise parents’ experiences as loss demonstrate higher or lower empathy towards these parents.

Although most studies reviewed included both mothers and fathers within their samples, fathers are still under-represented in the literature. Exploring the



experiences of fathers only may illuminate differences in the ways that mothers and fathers experience their child's mental health difficulties, or may alternatively confirm that the themes outlined here are equally applicable to men and women. Research from over 25 years ago demonstrated that there are gender differences in the frequency and trajectory of chronic sorrow amongst parents of disabled children (Damrosch & Perry, 1989); however future research would benefit from exploring whether gender differences exist in today's context.

Non-traditional families, such as same-sex parents or step-parents, have also received little attention within this field to date. Three of the studies included non-biological parents who were legal guardians within their samples but none looked at exclusively at this. In light of the current theories surrounding the role of genetics in mental health it would be interesting to explore their experiences further.

### **Conclusion**

The experience of having a child with mental health difficulties may be particularly emotionally distressing due to a number of losses that parents can experience. There are many similarities between the experiences of parents of adult and non-adult children and theories relating to grief and loss may be of relevance for both parties. Parents whose children are adolescents, however, may experience higher levels of uncertainty. Many of these ambiguities relate to

unique challenges relevant to this age group, such as the ambiguity of 'normal' versus 'abnormal' behavioural changes and the way in which responsibility and adulthood are defined by mental health services for young people. Developing a deeper understanding of how parents make sense of this ambiguity may enable suitable interventions to be discovered.

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**MAJOR RESEARCH PROJECT**  
**SECTION B: EMPRICIAL PAPER**

A narrative study exploring how parents make sense of  
adolescent mental health difficulties

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## Abstract

*Objective* – Research has shown that having a child who experiences mental health difficulties can be highly stressful for parents and may lead to feelings associated with loss and grief. Currently little is known about how best to support these parents' needs. Studies from a variety of fields suggest that the ability to find meaning in stressful life events is associated with decreased distress. The current study therefore sought to explore the ways in which a sample of parents whose adolescent children were experiencing mental health difficulties made sense of their experiences.

*Method* – Individual unstructured interviews were carried out with a sample of parents whose children were inpatients at an adolescent psychiatric hospital. A total of eight parents took part in the study, four male and four female. Interviews were audio recorded, transcribed verbatim and analysed using thematic and structural narrative analyses.

*Results* – The results suggested that parents varied in their extent and use of meaning making, with some able to find positive meaning in their child's difficulties and others struggling to make sense of it. Four master themes emerged across participants; unpredictability and ambiguity, difficulties identifying mental health difficulties, difficulties accepting the gravity of the situation, and benefits.

*Conclusions* - The findings of this study suggest that parents would benefit from having the ambiguity of their child's difficulties acknowledged. Interventions aimed at aiding meaning making should be offered to parents who struggle to make sense of their child's difficulties.

Keywords: Parent, Adolescent, Psychiatric, Narrative, Meaning

## **Introduction**

### **Loss and grief in parents of children who experience mental health difficulties**

Exploration into the experiences of parents whose adolescent children experience mental health difficulties has been relatively recent. Research with this group suggests that parents may experience a number of losses related to their child's onset of mental health difficulties. It has also been shown that parents frequently report feeling as though professionals working within these services tend to overlook their emotional needs. One possible reason for this finding is that parents of children with mental health difficulties may be experiencing disenfranchised grief (MacGregor, 1994). Disenfranchised grief has been described as a grief reaction that is socially unacknowledged (Doka, 1989).

Several factors have been outlined that increase the likelihood that parents of children with mental health difficulties are susceptible to disenfranchised grief. For example, the communities around these parents rarely perceive their experiences as a loss because their child is still alive, or in other words, that their grief may in part go unrecognised because it is an ambiguous loss (Boss, 1989). Furthermore, MacGregor (1994) also suggested that mental health professionals often misinterpret parents' grief reactions to their child's mental health difficulties as pathological.

### **The development of theories of coping with grief and loss**

Traditional Westernised theories of grief were built upon the positivist and individualistic nature of Modernism (Silverman & Klass, 1996). These theories posited that in order to resolve their loss, griever had to 'let go' of their bereavement by emotionally detaching from the deceased (Davies, 2004). It was thought that griever had to break these attachments in order to 'move on' and invest their emotional energy in forming new ones (Silverman & Klass, 1996).

Since the growth of Postmodernism in the late 20<sup>th</sup> century, there has been a shift in the understanding of grief and consequent approaches to helping people resolve their losses (Hall, 2011). Rather than breaking bonds with the deceased, research into the experiences of bereaved individuals has suggested that they may actually find value in continuing a symbolic bond with their lost loved ones (Silverman & Klass, 1996). However research also suggests that continuing bonds are not always deemed to be adaptive (Hall, 2011). For example, the style of a person's attachment bond with the deceased has been shown to determine whether the continuing bond can be used effectively (Field, Gao & Paderna, 2005). Neimeyer, Baldwin and Gillies (2006) have demonstrated that the ability to make sense of the loss also mediates the helpfulness of the continuing bond, leading them to conclude that those who maintain a close bond with the deceased but who are unable to find meaning in the loss are at greatest risk of distress. Indeed, at the heart of a number of contemporary theories of loss and stressful life events is the important role of meaning making (Gillies & Neimeyer, 2006).

### **The role of meaning making in loss**

There are a number of theories that attempt to address the relationship between stressful life events and meaning making, the majority of which come from the bereavement field. Although the terminology that theorists use varies, there seems to be a consensus that individuals experience distress when a stressful event, such as a loss, is at odds with their existing understanding of the world (Janoff-Bulman, 1992; Park, 2010; Neimeyer, Prigerson & Davies, 2002). In order to reduce the distress that this discrepancy creates, individuals must search for new meanings through the process of meaning reconstruction.

In the last two decades there has been increasing interest in the processes through which individuals attempt to reconstruct meaning following loss. Attempts to uncover the unconscious mechanisms through which people achieve meaning reconstruction have grown exponentially in recent years and are continuing to be developed, integrated and refined.

Kunkel, Dennis and Garner (2014) recently presented an integrated model of meaning reconstruction based upon a number of related theories. They proposed that there are four primary types of meaning reconstruction that people engage in following a loss. Firstly, *sense making*, as originally described by Gillies and Neimeyer (2006), is the process of finding reasons or explanations for the loss. It is therefore often related to attempts to find answers to 'why' questions. The second type of meaning reconstruction is *acceptance or resignation without understanding*. This is the cessation of attempts to find reasons or explanations when none can be found, and a subsequent tolerance for



the fact that no sense can be made of the loss. Thirdly, *realisation of benefits via positive reappraisal* is the process of finding a ‘silver lining’ (Holland et al, 2006) in the consequences of the loss, such as opening up new opportunities or changing an aspect of one’s life for the better. The final type of meaning reconstruction, *realignment of roles and relationships*, involves adopting new roles or identities within the world or adapting relationships with loved ones as a consequence of the loss.

In a related field of research, Boss (2006) has provided a number of therapeutic suggestions for helping people to resolve ambiguous losses (Table 1). Many of her suggestions overlap considerably with the types of meaning reconstruction outlined by Kunkel et al (2014).

Table 1  
*Boss’ (2006) six guidelines for therapeutic input for treating ambiguous loss*

Therapeutic goals	Definition
Finding meaning	Finding some form of positive meaning in the loss
Tempering mastery	Having a sense of control over one’s life
Reconstructing identity	Revising roles and family values in relation to the loss
Normalising ambivalence	Acknowledging and tolerating conflicting emotions
Revising attachment	Developing a new relational connection with the lost loved one
Discovering hope	Believing in the possibility of a positive future

Recent research provides preliminary support for the notion that meaning reconstruction can be a protective coping strategy when managing loss (Flesner, 2013). For example, studies of parents who experience the death of a child have demonstrated that meaning making is the strongest predictor of grief severity (Keesee, Currier & Neimeyer, 2008) and correlates with increased marital satisfaction, physical health and mental wellbeing (Murphy, Johnson & Lohan, 2003).

The findings of these studies however need to be interpreted with caution for two main reasons. Firstly, the majority of these experimental studies come from the same research group that has developed the meaning reconstruction model. The results of these studies may therefore be more susceptible to researcher bias, as the authors may have a conflict of interest in ensuring that experimental findings support their theory. Secondly, the methods used to measure aspects of meaning making to date have relied on self-report Likert-scale ratings to direct questions such as “how much sense would you say you have made of the loss?” (Holland, Currier & Neimeyer, 2006, p.180) or “do you feel that you are different, or that your sense of identity has changed, as a result of this loss?” (Neimeyer, Baldwin & Gillies, 2006, p.724). These methods have been criticised for being overly simplistic, as respondents are likely to interpret the questions differently and as such these measures may lack validity (Park, 2008). They also fall short of exploring *how* participants make meaning. In order to overcome some of these limitations Park (2010) has suggested that future research includes the “analysis of natural language” (p. 291).

### **Narrative as a means of meaning making**

Storytelling is considered to be the most natural form of human communication and a key way in which individuals make sense of the world around them (McAdams & McLean, 2013; Murray, 2003). Narrative is therefore thought to be a means of bringing “order to disorder” (Murray, 2003, p.97). Narrative identity theory posits that individuals make sense of their lived experiences through the ongoing construction and reconstruction of stories (Singer, 2004). Narratives can therefore be viewed as social constructions that are continuously revised in the context of interactions with others (Gergen & Gergen, 1988).

### **Rationale for current study**

Although research to date has looked at the experiences of parents, there has been little exploration of *how they make sense* of their child having mental health difficulties (Pejlert, 2001). Within Western cultures, the main aim of parenting is thought to be to produce a “well-socialised, healthy, happy child” (Harden, 2005, p. 208). It has been suggested, therefore, that when childhood mental health problems arise, this may cause parents to have to reconstruct their worldviews in order to make sense of this experience (MacGregor, 1994). Together with existing literature suggesting that parents of adolescents with mental health difficulties may experience ambiguous loss, these findings suggest that theories of grief and loss may be applicable to parents of these children.

Meaning making has been identified as a key process through which distress is reduced after the experience of loss. Theories of meaning reconstruction

outlined above overlap considerably with Boss' (1999) work on ambiguous loss and with MacGregor's (1994) suggestion that parents of children with mental health difficulties may have to reconstruct their worldviews in order to make sense of this loss. However, the application of meaning making models to date has largely been limited to the experiences of bereaved individuals. This study therefore aimed to explore how parents make sense of their child's mental health difficulties. The current study also sought to address limitations of existing quantitative research into meaning reconstruction and deepen our understanding of how people may engage in this by exploring individuals' naturally occurring language.

### **Research questions**

This study therefore sought to address the following research questions:

1. What stories do parents tell about how their adolescent child's mental health difficulties have impacted on them?
2. What do parents' narratives suggest about how they make sense of their adolescent child's mental health difficulties?
3. What do parents' narratives suggest about how best to meet their needs?

## **Methodology**

### **The choice of methodology**

Qualitative studies to date that have explored the experiences of parents whose children experience mental health difficulties have tended to rely on methods

that involve the development of themes. However it is difficult to sufficiently capture the complexity of people's lives and stories through thematic coding and for this reason it has been criticised as a reductionist technique (Lichtman, 2013). Furthermore, the process of fragmenting transcripts and taking participants' words out of the context in which they were told increases the possibility that their original meaning can get distorted (Riessman, 2008). Unlike other qualitative approaches, narrative analysis keeps the sequencing of stories intact in an attempt to stay close to narrators' meaning making (Squire, 2008).

Other qualitative methods also focus on the way in which individuals make sense of their experiences, such as Interpretative Phenomenological Analysis (IPA).

However whilst IPA is concerned with *content* of what is said, it does not focus on the *process* of participants' accounts. Narrative analysis explores both what is said and how it is said, with the latter being able to provide additional insights into how participants construct events (Riessman, 1989). However by focusing only on the stories that participants tell, narrative analysis excludes other information that could also be of value.

### **Epistemological Position**

Rather than adopting a positivist stance and viewing the stories as revelations about parents' 'true' selves, they were instead viewed as being shaped by the context in which they were told (Riessman, 2001). In line with social constructionist ideas, stories are thought to be co-constructed between the speaker and listener in narrative analysis (Squire, 2008). As such, the stories that parents told within the context of the current study may differ from those told in other contexts and with other interviewers.

## **Design**

The study employed a single measures design, using individual unstructured interviews with parents of adolescents who were currently inpatients at a psychiatric unit.

## **Participants**

A total of 12 parents were approached by the researcher, of which eight agreed to take part. Two parents reported that they were unable to spare the time required for the interview whilst juggling other commitments. One parent was unable to take part as their child was due to be discharged from the unit imminently and one declined to take part after reading the information sheet but did not specify their reason.

## **Inclusion and exclusion criteria**

The selection criteria were intentionally broad in order to obtain a diverse sample and as such demographic factors were not utilised as inclusion or exclusion criteria. Parents were deemed to be suitable for the study if they met the following criteria. Firstly, participants had to have been fulfilling a parent or carer role for the adolescent prior to their admission. Parents who were not in regular contact with their children or who were not actively involved in their care were excluded from the study. Secondly, their adolescent child had to be a current inpatient on the unit and had to have been admitted at least two weeks previously. Those whose children had been discharged from the unit prior to the research interview, or who had been an inpatient for less than two weeks, were excluded. The minimum two-week admission criterion was intended to allow

parents time to adjust to the situation, to develop an understanding of the unit and to begin a relationship with the nursing staff before taking part in research.

A total of eight parents of seven adolescents took part in the study, four male and four female. Both parents of one adolescent took part, although they were interviewed individually. The adolescents ranged in age from 13 to 17 and presented with a variety of mental health presentations. The researcher intended to immerse themselves as fully as possible in parents' understandings and as such had no access to their child's medical records. The information provided in Table 2 was therefore collected directly from the parents themselves.

Table 2  
*A Summary of Parent and Adolescent Demographics.*

Pseudonym	Parent Gender	Adolescent Gender	Adolescent Age	Length of admission at time of interview	Adolescent's diagnosis, as reported by parent	Number of admissions inclusive of current one
Graham	Father	Son	16 - 17	2 – 4 weeks	Asperger's Syndrome & Depression	1
Tanya	Mother	Daughter	13 - 15	5 – 8 weeks	Borderline Personality Disorder & Psychosis	3
Duncan*	Father	Daughter	16 - 17	5 – 8 weeks	Possible Depression or Anxiety disorder	1
Caroline*	Mother					
Steve	Father	Son	13 - 15	2 – 4 weeks	ADHD, Speech & Language difficulties & Depression	1
Miriam	Mother	Son	16 – 17	17+ weeks	Autism Spectrum Disorder & Schizoaffective disorder	1
Beverley	Mother	Daughter	13 – 15	9 – 16 weeks	Emotional Dysregulation & Depression	1
Nigel	Father	Daughter	16 - 17	9 – 16 weeks	Borderline Personality Disorder	2

*Note.* \*These two parents spoke about the same adolescent.

## Procedure

### Recruitment.

The researcher's only involvement with the unit was for the purpose of the current research; they were not based at the recruitment site for a placement or for any other clinical work. Participants were therefore informed of the study by the clinical team and were asked whether they would like to be contacted by the



researcher to find out more about it. If parents consented to this then their contact details were securely passed onto the researcher via the external supervisor. The researcher then contacted the parents by telephone, explained what the study entailed and offered to send them the information sheet (Appendix A) and consent form (Appendix B) via email. If parents agreed to be sent these documents then this was followed up with a second telephone call at an agreed time to determine whether parents would be interested in taking part. Those who expressed an interest were invited to attend an interview on a date and time that suited them, which in the majority of instances coincided with their pre-existing visiting arrangements to the unit.

### **Interviews.**

The interview schedule (Appendix C) was developed in line with the narrative interview technique outlined by Jovchelovitch and Bauer (2000). This suggested procedure was chosen as it aims to minimise the researcher's influence by ensuring that they do not impose a structure on the interview.

All parents were interviewed at the mental health unit where their adolescent child was an inpatient. Each meeting lasted a maximum of 90 minutes, which included answering any outstanding queries, explaining the format of the interview, signing the consent form, the interview itself and debriefing. The length of the recorded interview varied slightly depending on how much parents shared but the mean duration was 55 minutes.

Interviews were conducted at the inpatient unit, for both parents' convenience and the researcher's safety. However it is important to consider that this context was far from neutral for parents. The 'family room' in which the interviews were conducted was regularly used for family meetings by the clinical team and as such it was a familiar space for parents. During their interviews some parents referred to previous meetings that they had had with the clinical team in the same room, often regarding past events that were highly emotive. Alternative clinical spaces could have been utilised in order to avoid this but were not done so for several reasons. Firstly, all other bookable rooms were located on the ward itself, whereas the family room was located off of the main reception area. For safety reasons all of the rooms on the ward contained transparent glass and as such parents' anonymity from the clinical team would have been impossible to preserve if interviews were held in these spaces. It was also felt that conducting interviews within view of the adolescents could have caused disruption for both parents and their children. In contrast the family room was a confidential space that could be accessed without the assistance of members of the clinical team. This ensured that only the receptionist, researcher and researcher's supervisor were aware of which parents had participated in the study.

## **Data Analysis**

### **Background.**

The narrative transcripts were analysed using a combination of thematic and structural narrative approaches, to look at both *what* was said and *how* it was

said. Narrative researchers frequently combine more than one approach, in order to gain a richer understanding of the data (Frost, 2009). Although there is no set way in which to carry out a narrative analysis, it is common practice to begin with a structural analysis as it assists the researcher in locating what the purpose, or evaluation, of the story is for the narrator (Riessman, 1993).

### **Procedure.**

The researcher initially transcribed all of the audio recordings of the interviews verbatim, including repetitions, pauses and gestures. The data analysis then involved a number of steps, using McCormack's (2000) multiple lenses as a means of interpreting the data. The first step was active listening, which involved listening to each audio recording several times and noting my initial responses to the data whilst holding in mind the questions contained in Table 3 (McCormack, 2004).

Table 3  
*McCormack's stages of active listening*

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Who are the characters?

---

What are the main events? Where/When do they occur?

---

As researcher, how am I positioned in relation to the participant?

---

How am I responding emotionally and intellectually to this participant?

---

This stage helped me to familiarise myself with parents' stories, immerse myself in the data and bring awareness to my own assumptions at an early stage of analysis.

The second stage of analysis was to identify the smaller stories within the overarching narratives (McCormack, 2000). This involved paying close attention to the structure of the stories by applying Labov and Waletzky's (1967) structural framework (Table 4).

Table 4  
*Labov & Waletzky's (1967) structural framework*

Abstract	A plot summary
Orientation	Information about who, what, when and where
Complicating action	The sequence of events leading up to a climax, turning point or crisis
Evaluation	The point of a story
Resolution	The outcome of a story
Coda	A signal that marks the end of a story, usually achieved by returning to the present tense

It is worth noting that not all narratives contained each of these elements; only the complicating action is considered necessary to constitute a story (Labov, 1972). Focusing on the way in which stories were structured enabled the researcher to determine the salient points that parents were trying to convey through their narratives. The way in which narrators structure their stories can also provide further information about how they make sense of the events they narrate (Riessman, 1989). Storytellers may, for example, keep the listener in suspense by delaying the complicating action. An example of this structural analysis can be found in Appendix D.

The third stage of analysis required paying closer attention to the language used by participants. McCormack (2000) suggested focusing on two main aspects of language: *what* is said (including vocabulary choices, phrases, words that assume common knowledge, specialised vocabulary) and *how* it is said (including intonation, pauses, stutters, metaphors, repetition, accentuation, agency).

After approaching the transcripts through these different lenses, a thematic narrative analysis was then performed. This involved paying close attention the ways in which parents made sense of their experiences through the stories that they told. Following analysis at an individual level, similarities and differences were then compared between cases. Initial themes that related to similar constructs were grouped together into 13 subthemes and then refined further, which resulted in a total of four master themes.

### **Quality Assurance**

Quality guidelines suggested for qualitative research were adhered to wherever possible (Mays & Pope, 2000). This involved leaving an audit trail of the data analysis, performing a deviant case analysis and an emphasis on researcher reflexivity. Prior to commencing data collection, I conducted a bracketing interview in order to increase my awareness of my own assumptions about the research topic. I met with a fellow trainee psychologist who conducted a semi-structured interview in order to explore my knowledge of the topic and my personal relationship to it (Appendix F). Although these questions formed the framework for the interview, the interviewer explored my responses further

with curiosity. This process revealed a number of assumptions, including that parents would have been the ones to initially seek help, or facilitate the hospital admission, that they would voice criticism of mental health professionals, that themes of guilt and blame would inevitably emerge in their narratives and that they would be able to identify positive elements of their difficult experiences. I also kept a reflective research diary (Appendix G) to monitor my thoughts, opinions and reactions throughout the research process. I also compared my analysis with my internal supervisor, to check that assumptions were not interfering with the analysis and that conclusions were derived from the data.

### **Ethical Considerations**

The study was granted ethical approval by a NHS Ethics Committee (Appendix H) and the researcher adhered to the professional Code of Human Research Ethics (British Psychological Society, 2010) throughout the research study. This included ensuring participant anonymity, maintaining confidentiality, gaining informed consent and utilising secure storage of audio recordings and transcripts. Several procedures were put in place to reduce the possibility of parents becoming distressed as a result of the interview, including a thorough debriefing and the opportunity to have a follow-up session with a qualified clinical psychologist. Although parents frequently became emotional when discussing their experiences, they often described the interviews as thought provoking or therapeutic and none of them felt that they required a follow-up session.

## Results

The following results are presented in two sections. Firstly, a summary of each narrative is provided, followed by the results of the thematic narrative analysis. Direct quotations are presented in italics; commas reflect momentary pauses in speech, whilst the lengths of longer pauses are denoted by the bracketed number of seconds, and bracketed ellipses indicate that some text has been removed.

### **What stories do parents tell about how their adolescent child's mental health difficulties have impacted on them?**

#### **Narrative Summaries**

##### **Graham**

Graham spoke at length about his son's self-harm and suicidal behaviour, although structurally his stories often lacked a resolution. This seemed to reflect the sense of powerlessness that he portrayed throughout his narrative. He positioned himself as at the mercy of his son's behaviour and expressed his horror at his inability to predict when the next incident of self-harm would come. The uncertainty of his son's mental health trajectory, and more pressingly the inability to know whether his son would successfully commit suicide, were clearly very painful experiences for Graham. Throughout his narrative he referred to having lost the certainty that he once felt about his and his son's lives. For example, he noted that he used to believe he would outlive his son but that he now had to "*accept that I, one day I might be burying him*".

### **Tanya**

When telling her initial narrative, Tanya chose to tell a series of small stories which seemed to reflect the number of false starts she experienced when trying to get help for her daughter. Many of her stories related to the exasperation she felt with services they encountered prior to the hospital admission and in particular the way in which her daughter was treated punitively. For example, when discussing the response at the local Accident and Emergency department she said about her daughter *"it's as if she was a real pain, pain in the backside and they really, really could do without the hassle"* and in relation to the police *"I mean she's not a, she's not a cri-serial murder or anything like that she's just a (3) a normal 15 year old girl that's a bit troubled"*. Her daughter had a long history of input from mental health services and Tanya described how the fluctuations in her daughter's mental health and associated events had left her feeling *"completely numb"*.

### **Duncan**

The majority of Duncan's narrative focused on the immediate hours prior to his daughter's hospital admission. He told a series of short stories in which he got things done by approaching problems logically in order to find solutions. Although Duncan spoke about the practical aspects of his parental role, he rarely acknowledged the emotional impact of his daughter's situation. Duncan was an



ambulance worker and he drew heavily on his professional experience of remaining calm in crisis situations at work:

*I tried to remain emotionally detached, partially for my own (4) er protection but also um so that I was (3) um (2) more in control of thoughts about what I needed to do for her care um I just (3) touched back into that and brought it forwards so that I could um (1) have a better grasp of what was going on and not get emotional about it*

Throughout his narrative he used medical terminology and he seemed to find it relatively easy to make sense of his daughter's difficulties due to his professional familiarity with health services.

*I haven't really got an opinion as a parent because um I was er in the ambulance service anyway and um I know yknow [...] I've got a fair understanding of what to expect so I, I didn't have any parental opinion or um not opinion, I didn't have any parental um expectations or inhibitions, er I just knew that anyway*

His narratives often involved him fulfilling a liaison role between his daughter and the clinical team. Duncan was also the only parent in the study who was not living with their adolescent child prior to their admission; his daughter was living with Duncan's ex-partner Caroline, who was also interviewed. It is possible then that his physical distance from his daughter may have been adaptive in helping him to cope with her difficulties.

### **Caroline**

Caroline spoke throughout her narrative about the difficulty of being a single parent to three children and the somewhat impossible task of trying to "juggle" their needs. Her stories related mainly to the practical aspects of care that she provided for her children, and the impact that a series of events had had on them. However her narrative contained relatively little about how she herself

had been impacted. Caroline seemed to express difficulty in finding meaning from her daughter's experience of mental health difficulties, as noted in her opening few sentences when she said

*Um (3) I don't know, the immediate situation we're in kind of seems like the place to start because its obviously the one that's right in the face but at the same time its not the one I completely understand either*

Caroline often presented conflicting views when attempting to explain the sense she could make of her daughter's mental health difficulties. She tended to flit between seemingly blaming herself "in hindsight" for not realising sooner that her daughter needed help, or framing these missed opportunities in self-critical language such as "making excuses" before reminding herself that factors were often outside of her control.

*it's a very fine balance and obviously I didn't, quite get it right because she ended up in here, but at the same time I didn't have the answers for her*

### **Steve**

Steve was the participant who was least familiar with the unit, with his son having only been admitted recently. He was also the participant that seemed to find the structure of the narrative interview the most challenging, requiring several prompts to initiate him into storytelling.

Steve spoke about a number of adversities that he had faced throughout his life, including his own experience of mental health difficulties. However what remained throughout these stories was a resolution of "having faith" and he portrayed a sense of needing to overcome his vulnerability to be "strong" and

"fight" for his children. He spoke about his son in a similar way; that his son would overcome his difficulties to "become a better person".

*um, I mean it is hard day by day, but what keeps me going is that, I've got a lot of hope and a lot of faith and like yknow so that's what (2) will keep us going and that's what, I keep drumming it into him as well*

### **Miriam**

Miriam's son was approaching the end of a lengthy admission and her narrative focused mainly on the journey of his admission, more so than the events preceding it as other parents had done. She likened her early experiences of her son's admission into the unit to a grief process.

*well initially it was very very hard, cos it was new, it was different, it was (4) is this really happening, it was shock, it was shock, yknow I think, in a way, it was a little bit like grieving, right, because (3) you've lost your boy, yeah, as he was, so I felt like to an extent I was grieving*

Although she described the grief as a past feeling, she came back to the theme of "not knowing" throughout her narrative to explain her uncertainty about what lay ahead for her and her son.

*it's the not knowing again, not knowing what, what, what is it going to look like when he comes home, how is it gonna be, how is this gonna effect our lives yknow, is he gonna have a relapse, I'm worrying about that, I, I think, is this just a one off or is it a re-is he going to have a relapse, is he gonna be permanently on and off ill, yknow and I, I'm scared about that cos I don't want him to have a relapse, don't want him to go backwards*

### **Beverley**

Beverley's narratives tended to contain large amount of evaluative clauses and she described herself as someone who was "*open-minded*" and not "*too phased*" by her daughter's self-harm. She described a constant "*element of denial*" which she felt was protecting her from the emotional impact of facing the reality of her daughter's suicidal wishes.

She spoke of her own "*philosophy of being open-minded*", but she also spoke of her daughter's "*philosophy [...] that life isn't worth living*". Rather than viewing her daughter's difficulties as behaviours, as other parents did, she instead viewed them as part of her daughter's personality, describing her as someone who would "*always be someone with problems and with er a (3) a (3) tendency, yknow, to, be very dark*". Beverley described the revelation that her daughter had began self-harming as "*not expected, completely unexpected but not a surprise either*". She attributed this reaction, in part, to her own experiences of mental health and of experimenting with self-harm as a teenager herself.

### **Nigel**

Nigel drew heavily on professional language to make sense of his daughter's mental health difficulties. He talked about books he had bought, films he had watched, documentaries he had seen, and he seemed to find some solace in the advice and information found within these sources. Nigel seemed to be searching for answers within these sources regarding his daughter's future and he fluctuated throughout his narrative between feeling hopeful that she would recover and "*logically knowing*" that "*borderline personality doesn't go away, that's the problem*".

### **What do parents' narratives suggest about how they make sense of their adolescent child's mental health difficulties?**

Four master themes emerged from the thematic narrative analysis: unpredictability and ambiguity; difficulties identifying mental health difficulties; difficulties accepting the gravity of the situation; and benefits (Appendix E).

#### **Unpredictability and ambiguity**

The theme of ambiguity ran throughout parents' narratives and was present in stories they told about their children's past, present and future. Parents often described the onset of their child's mental health difficulties as coming completely out of the blue. In terms of current narratives, several parents noted that they were often taken aback by an increase in their child's symptoms at times when they had thought things were improving. This unpredictability and cyclical nature of difficulties often left parents feeling powerless and unable to make sense of their child's difficulties. Particularly prominent was the uncertainty parents voiced about the future for their child, a theme that has been demonstrated previously in the literature. One of the most frightening aspects for some parents was the ambiguity of whether their child would end their lives through suicide and it was these parents in particular who seemed to demonstrate the highest levels of distress. Many parents expressed a hope that

their child's difficulties would not continue past adolescence, whilst also acknowledging the ambiguity of this.

### **Difficulties identifying mental health difficulties**

Almost all of the participants described significant shock when they first found out about their child's mental health difficulties, often initially through evidence of self-harm. Many of the parents in this study however seemed to be trying to make sense of this retrospectively and speculated about possible missed signs. For example, the difficulty in distinguishing between typical teenage fluctuations in mood and changes indicative of a mental health difficulty emerged from the data in this study, supporting previous research with this population. Several parents described how their child seemed to conceal their self-harm from them and as such they remained oblivious to it for quite some time. Some parents in the study also drew on wider cultural narratives relating to causation that are located within the family context, such as domestic violence, divorce and neglectful parenting. However it was often the case that parents would express an inability to comprehend why their child had developed mental health problems in the absence of these factors. This confusion often led to them wondering whether they had done something 'wrong' without realising it or doubting themselves. Parents were often noted to move between doubt and belief in their parenting abilities during their narratives.

### **Difficulties accepting the gravity of the situation**

When describing their past narratives, some parents seemed to describe how they had been unable to allow themselves to consider the possibility that their child may have mental health difficulties. Several parents initially believed that their child's hospitalisation would be a quick fix and that their difficulties would be solved easily. Other parents likened their feelings to early stages of grieving in which emotions are numbed. Parents generally seemed to be unable to find meaning in their child's self-harming behaviours and would often explicitly state that they struggled to understand how their children could want to harm or kill themselves. In order to cope with the gravity of their situation, several parents described emotional detachment and denial as protective coping strategies.

### **Benefits**

An interesting finding was that half of the parents interviewed were able to identify benefits to their child's difficulties, or to the hospital admission itself. These included having a better understanding of their child's needs, a stronger relationship with their child, increased awareness of other people's distress and a desire to offer them support, and a sense that their child may become a stronger or better person as a result of overcoming difficulties. This is an important finding as there are currently very few social narratives of hope or benefit for parents of children with mental health difficulties.

## Discussion

### **What do parents' stories suggest about how best to meet their needs?**

The narratives outlined briefly above highlight the variety of ways in which different parents made sense of their adolescent child's mental health difficulties. The complexity and variety of meaning making in the narratives demonstrate the importance of understanding how each parent makes sense of their individual experiences.

Whilst there was a range of narrative structures employed to different effects, the majority of parents seemed to demonstrate some difficulties in making sense of their child's situation. The continual shocks and the difficulty coming to terms with the reality of their child's situation suggested that for some parents their child having mental health difficulties may have been at odds with their existing worldview as MacGregor (1994) suggested. Many of the parents in this study reported high levels of distress and research has suggested that this distress can be lessened through the process of finding meaning out of stressful life events.

Although these parents seemed to be in the process of trying to make sense of their child's situation, for some their current ways of managing seemed to be to detach themselves from their painful experiences. When writing on chronic sorrow, Olshansky (1962) noted that 'such regression may help the parent to tolerate better the terrible reality that confronts him each day' (p.191). It seems likely however that denial may prevent meanings from being found. Other



parents likened their experiences to a grieving process; of coming to terms with the potential loss of the child they previously knew. That two parents likened their experiences to grieving without any prompts from the researcher gives weight to the view that theories of loss and grief may be applicable to some parents of adolescents with mental health difficulties.

The prevalence of themes relating to uncertainty and ambiguity across the data provides some support for the notion that the theory of ambiguous loss may be of relevance for some parents of adolescent children with mental health difficulties. Indeed it seemed to be the ambiguity of their child's difficulties that was often preventing them from finding meaning. Conceptualising some parents' experiences as ambiguous loss may not only allow their experiences to be acknowledged rather than disenfranchised, but it may also open up possibilities for intervention. Interventions aimed at managing ambiguous loss tend to focus on assisting individuals to find new meanings, which in turn leads to lowered distress. Boss' (2006) suggestions for therapeutic intervention also focus on empowering parents and may be a useful means of overcoming some of the powerlessness they reported.

However it is worth noting that some parents were more able to engage in adaptive meaning making, suggesting that their child having mental health difficulties could have been, or had become, consistent with their global beliefs or worldview. In these instances parents were able to find value in their child's

difficulties or hospitalisation and this type of benefit finding has been purported to be a protective factor against future grief.

Interestingly, themes of guilt and blame were not as prominent as research to date would suggest they might be. It seems that without such prompting, these themes appear less frequently and it may be that the current literature places too much importance on them in comparison to what parents feel is most salient. Some parents drew on implied dominant narratives that suggest that parents perhaps *should* blame themselves but they struggled to see how they could have done anything differently. That parents did not tend to blame themselves for their child's difficulties is likely to be a positive finding, as self-blame is likely to have a detrimental impact on parents' wellbeing (Moses, 2010).

### **Strengths and Limitations**

A strength of this study was the grounding in current theory and its application to a novel population. Another strength was the inclusion of fathers' perspectives, who were equally represented within the sample. Most papers contain samples in which fathers are either non-existent, or are in the minority, and so this study may more accurately reflect parents' experiences rather than solely mothers' experiences. As with all qualitative research, the results are not intended to be fully generalisable but it is hoped that this research will help to highlight the importance of working with parents to understand how they make sense of their experiences.

A limitation of this study was the lack of audit of the initial recruitment process. The researcher was reliant on the clinical team to initially determine parents' interest in the study and unfortunately no record was kept of how many parents declined to be sent the information sheet or their reasons for doing so. It is possible however that parents who found it harder to find meaning in their child's difficulties were less likely to participate in the narrative interview, resulting in a biased sample.

In order to gain as rich a data set as possible, narrative analysis aims to utilise heterogeneous sampling. The current study sought to gain a varied sample and achieved this in relation to gender, length of hospital admission and child's diagnosis. However there was a lack of cultural diversity within the sample, with seven out of the eight parents identifying themselves as White British. Although this was representative of the wider population within which the research was carried out, it is known that culture has a significant impact on the narratives that individuals tell (Riessman, 1993). As such the results of this study may not reflect the experiences of parents from other cultural backgrounds.

Although the study was open to both parents and carers, only biological parents chose to take part. Over the course of the recruitment phase it was reported by the clinical team that relatively few of the inpatients were looked after by non-biological parents, although for confidentiality purposes the researcher did not have access to this information. However on reflection the researcher felt it was important to consider another possible explanation for this. Despite the

information sheet explicitly stating that non-biological parents would be eligible to take part, and the title of the study referring to parents and carers, much of the information detailed within this document privileged the term 'parents' rather than 'parents and carers'. Therefore the possibility that carers were inadvertently discouraged from taking part as a result of the language used cannot be eliminated.

Respondent validation, as suggested in quality assurance guidelines for qualitative research, was not sought following data analysis (Mays & Pope, 2000). This could be considered a further limitation of the current study, as it is possible that the researcher misinterpreted parents' original meaning. However some narrative researchers have argued that seeking participant feedback does not effectively reduce this risk and have suggested that alternative methods of increasing credibility are used (Riessman, 1993). Additional steps that were taken included an ongoing awareness of researcher assumptions and biases, as well as comparisons of independent analyses with supervisors.

### **Implications for practice**

This research suggests that the ways in which parents make sense of their child's mental health difficulties vary significantly. It highlights the importance of getting to understand the way in which each parent constructs or reconstructs meaning in the context of their child's difficulties.

The findings from this study may help professionals to determine which parents may be in need of most support or may be at risk of prolonged distress. A helpful first step for clinicians working with parents of children with mental health difficulties would be to explore whether parents seem able to comprehend their situation by focusing on the aspects of meaning reconstruction discussed above.

Helping parents to tolerate the ambiguity of their child's difficulties is likely to be a useful approach for all parents regardless of their ability to make sense of their difficulties. Professionals may sometimes feel a pressure to not acknowledge the ambiguity, as they may feel that it could feel uncontainable for parents to hear that they too do not know what the future will hold for their child. However this research suggests that some parents may benefit from being able to talk openly with professionals about the uncertainty and associated feelings that accompany this. One useful approach for helping parents tolerate the ambiguity is to use the both/and approach in order to encourage parents to accept that there may be more than one possibility (Boss, 2006).

In instances where parents seem unable to make sense of their child's difficulties, Boss' (2006) suggestions for therapeutic intervention may provide helpful guidance for clinicians. For example, if parents describe a sense of helplessness, then professionals could consider an intervention that focuses on 'tempering mastery'. This includes externalising blame, helping the parent to identify past competencies and accepting an imperfect situation, so that the parent is able to feel as though they are "choosing to accept and live with the

ambiguity rather than continuing to perceive oneself as being the helpless victim of it” (Boss, 2006, p.103). Helping parents to find value in their child’s situation, albeit difficult, will also be particularly helpful.

Providing parents with opportunities to tell their stories is likely to lead to improved outcomes; however this can often be difficult to accommodate in busy mental health services. One suggestion is to consider the use of groups for parents to come and share their experiences with one another. It may be particularly helpful for parents who are struggling to make sense of their situation to hear from those who have been able to find some positive meaning and to begin to develop a shared narrative of their experiences. Not having opportunities to meet as a group has been shown to perpetuate powerlessness (Cooke, Daiches & Hickey, 2015) and as such the collectivism of a shared space may also help to empower parents.

### **Areas for further research**

The results of this study suggest that some parents of children with mental health difficulties may benefit from interventions aimed at promoting meaning making. Identifying suitable interventions and evaluating their efficacy for this population should therefore be a priority. Indeed, it has been noted that interventions aimed at promoting meaning making need to be rigorously tested more generally (Lichtenthal, Currier, Neimeyer & Keese, 2010).

Future research would benefit from testing the hypothesis that such interventions would decrease distress for parents of adolescents with mental health difficulties, ideally by employing an experimental design that includes a control condition. It is hypothesised that helping parents to find meaning in their child's difficulties may prevent complicated grief reactions such as chronic sorrow, by instead enabling a process of grieving which is associated with a gradual reduction in distress. The findings of this study also suggest that some parents are able to make sense of their adolescent child's mental health difficulties. A naturalistic study aimed at testing whether these parents have better long-term outcomes in terms of wellbeing would also be of value, as it may be that other factors besides meaning making impact on the distress associated with their child's mental health difficulties. Furthermore, it would also be valuable to determine factors that are associated with increased meaning making and the ability to find positives in the context of significantly stressful life events. Whilst theories outlined here suggest that it is a person's worldview that influences whether sense can be made of a stressful event, it would also be helpful to explore whether other factors can also contribute to this.

An interesting area to explore in further research would be whether and how parents' constructions of their child's difficulties impact on the adolescent's wellbeing and recovery.

Finally, it is hoped that this research will help pave the way for further research that aims to develop alternative, more helpful narratives for parents.

## **Conclusion**

In summary this research has shown that parents make sense of their child's mental health difficulties in a variety of ways. Whilst some parents are able to find meaning in their child's situation and can identify positives to this event, others struggle to make sense of this. It is hoped that this research has shown that parents of children with mental health difficulties are worthy of support in their own right. Conceptualising parents' experiences as ambiguous loss may provide professionals with a way forward for helping parents to find meaning and will hopefully reduce the risk of complicated grief reactions such as chronic sorrow.



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CERI R. JONES BA Hons

SECTION C: APPENDICES OF SUPPORTING MATERIAL

SALOMONS  
CANTERBURY CHRIST CHURCH UNIVERSITY

## Appendix A – Information Sheet

### Information about the research

#### Parental and carer narratives of acute adolescent distress

Hello. My name is Ceri Jones and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide it is important that you understand why the research is being done and what it would involve for you. You can discuss this study with a member of the clinical team at (*name of unit removed*) if you would like to.

Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

#### Part 1

##### **What is the purpose of the study?**

The purpose of the study is to find out more about how people who act as parents are impacted when an adolescent becomes unwell and needs admission into an inpatient unit. At present, little is known about how parents experience this and it is hoped that the findings of the study will help to improve our knowledge so that staff can work alongside parents more effectively. The study is being carried out as part of my doctoral training to become a qualified clinical psychologist at Canterbury Christ Church University.

##### **Why have I been invited?**

You have been invited to participate in the study as someone that usually takes care of an adolescent who has recently been admitted to (*name of unit removed*). The study is looking for people from a range of backgrounds, including mothers and fathers, as well as biological and non-biological parents. Approximately ten participants will be interviewed in total during the course of the study.

##### **Do I have to take part?**

Participation is entirely voluntary and it is up to you to decide to join the study. The study is completely separate from the care provided by the clinical team at (*name of unit removed*). This means that the clinical care that you or the young person in your family receives from the unit will not be influenced by your decision to take part in the study or not. If you agree to take part, then you will be asked to sign a consent form. You are free to withdraw from the study at any time and you do not need to give a reason for this.

##### **What will happen to me if I take part?**

If you have given consent to be contacted about the research, then I will call you to answer any questions you may have about the study and to check that you meet the inclusion criteria.

If you then decide to take part, you will be invited to attend an interview at (*name of unit removed*) at a time that suits you. The interview will be audio recorded so that it can be

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accurately transcribed afterwards. As I don't have access to any clinical information about you or your child, I will begin by asking you a little about yourself, such as your age and ethnicity. You will then be asked to talk about your experiences as a parent of a young person on the unit. Rather than being asked a specific set of questions, you will be encouraged to tell your own story and I will then ask you some questions in relation to what you share. The whole meeting will last a maximum of one and a half hours.

Following the interview, I will transcribe our conversation and change any personally identifiable information so that your anonymity is preserved. The transcript, together with the stories that the other participants tell, will then be analysed for common themes and patterns.

### **Expenses**

Your travel to (*name of unit removed*) will be reimbursed up to a total of £10. This will be paid to you in cash on the day of the interview.

### **What will I have to do?**

You will need to attend (*name of unit removed*) for an interview that will last a maximum of one and a half hours. The interview will be in English so you will need to be able to speak English fluently in order to take part. During this interview you will need to be willing to share some of your experiences with me.

### **What are the possible disadvantages and risks of taking part?**

Having a child admitted into hospital can bring up a range of feelings and it is possible that discussing some of your experiences may be upsetting for you. The interview will be held with this in mind and we will debrief fully before our meeting comes to an end. It is up to you what you discuss with me and you will not be asked to talk about anything that you are not comfortable to. It is also up to you whether you share any information about the study with your child. I am happy to discuss this decision with you further if you wish.

### **What are the possible benefits of taking part?**

Some people might value the process of telling their story and reflecting on their experiences to date. We cannot promise that the study will help you, but it is hoped that the findings will help to improve the service that parents receive from (*name of unit removed*) in the future.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

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## Part 2

### **What will happen if I don't want to carry on with the study?**

You can withdraw from the study at any time without giving a reason and with immediate effect. If you withdraw from the study, we would like to use the data collected up to your withdrawal.

### **What if there is a problem?**

If you find the content of the interview upsetting, then this will be handled sensitively within the interview itself. You will be offered the opportunity to take a break or terminate the interview if you wish. Should you feel distressed as a result of the interview and wish to speak to someone other than me, there will be a qualified member of the clinical team available on the ward. In the unlikely event that you remain distressed following the interview then you will also be offered the opportunity to meet with a qualified clinical psychologist for a one-off session.

### **Complaints**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have a concern about any aspect of this study, you should contact me in the first instance on (*telephone number removed*) and I will do my best to answer your questions. If I do not answer immediately please leave your name and contact number and I will return your call as soon as possible.

If you remain unhappy after speaking to me and wish to complain formally, please contact: (*name and contact details removed*)

### **Will my taking part in this study be kept confidential?**

Yes. Ethical and legal practice will be followed at all times during the study and all information about you will be handled in confidence. Confidentiality will only be broken if you disclose any information during the interview which indicates that you, or someone else, may have been harmed, or may be at risk of harm. In this instance it may be necessary to inform a member of the clinical team. In the unlikely event that confidentiality needs to be breached, I will discuss this with you beforehand.

I will be the only person who has access to identifiable data, such as your name. All information collected during the study will be anonymised. This means that when findings of the study are shared, including with the clinical team, then the participants will not be able to be recognised or identified.

Your interview will be audio recorded for the purposes of transcription using a digital recorder. Following the interview, the recording will be transferred to an encrypted memory stick and deleted from the digital audio recorder. Once the interviews have been transcribed then the recordings will also be deleted from the encrypted memory stick.

All transcripts will be anonymised and pseudonyms will be used when writing up the results. Any potentially identifiable information will also be altered to ensure anonymity. Copies of the anonymised transcripts will be kept securely in a locked filing cabinet on a

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password-protected CD at Canterbury Christ Church University for ten years and then destroyed.

**What will happen to the results of the research study?**

The results of the research study will initially be sent to participants and you will be offered the opportunity to feedback on the extent to which they accurately reflect your experiences. The study will then be written up for the purposes of an academic assignment and it is hoped that the findings will also be published in a scientific journal. Anonymised quotations from interviews will be used in the final reports but participants will never be identifiable.

**Who is organising and funding the research?**

The research has been funded by Canterbury Christ Church University and will be undertaken as part of the Doctor of Clinical Psychology degree offered by the university.

**Who has reviewed the study?**

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by a Research Ethics Committee.

**Further information and contact details**

For further information about the study please contact:

Name: Ceri Jones  
(*Contact details removed*)

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**Appendix B - Consent Form**

Title of Project: **Parental and carer narratives of acute adolescent distress**

Name of Researcher: **Ceri Jones**

Participant Identification Number for this study:

Please initial each of the following boxes.

1. I confirm that I have read and understand the information sheet (dated 06.11.14, version 2.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my or my child's clinical care or legal rights being affected.

3. I agree to my interview being audio recorded for the purposes of transcription.

4. I agree that anonymous quotes from my interview may be used in published reports of the study findings.

5. I agree to take part in the above study.

Name of Participant \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

Name of Person taking consent \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

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## **Appendix C – Interview Schedule**

In line with the procedure outlined by Jovchelovitch & Bauer (2000), the following basic rules of the narrative interview will be adhered to where possible.

### **Initiation**

The Chief Investigator will open all interviews with:

“Today is a chance to think about your own experiences of your child’s mental health and in what ways, if any, this has impacted on you. I wonder if there is a natural starting point to your story?”

### **Main narration**

The Chief Investigator will allow the parent to tell their story uninterrupted and will demonstrate active listening. During this phase, the Chief Investigator will also develop questions for the next section, based on the story being told.

Before moving on, the Chief Investigator will ask: “Is there anything else you want to say?”

### **Questioning phase**

The Chief Investigator will elicit additional or new information, using the following questions. At this stage the Chief Investigator will not ask ‘why’ questions, or questions that elicit opinions, attitudes or causes.

“What happened next?”

“What happened then?”

“What happened before/after that?”

“Could you tell me more about that time?”

“What do you remember from that time?”

### **Concluding talk**

The Chief Investigator will close the storytelling and allow a space for reflection. Why questions will be asked here if relevant.

“How was it talking to me today?”

“Do you have any questions?”

### **Prompts**

If however participants struggle to begin storytelling after the initiation phase, then the following prompts will be used to elicit a fuller narrative:

Can you remember when you first had concerns for your child’s wellbeing?

What was happening at that time?

How did you understand it at the time?

Was there anything that you did before getting help from services?

Was there a point at which it was clear that your child needed help from services?

How was the decision made to seek help for your child?

Who made it?

What was your experience of seeking help for your child?

What was the experience of your child being admitted like?

Has your child being here had any effect on how you see the family?

How do you imagine the journey ahead for you and your family?

**Appendix D – Example of Structural Analysis**

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**Appendix E - Examples of theme development**

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## **Appendix F- Bracketing Interview Questions**

Questions were adapted from Fischer, 2009.

1. What are you interested in as a researcher?
2. What attracted you to this area of research?
3. What in your own personal history connects you to themes in your research?
4. How might personal connections to your research influence the approach you take?
5. Has anything about reflecting on these questions surprised you?
6. What avenues might you be curious to explore further?



**Appendix G – Abridged Reflective Research Diary**

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**Appendix H - Ethics Approval**

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**Appendix I -Author Guidelines**

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**Appendix J - End of Study Declaration**

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## **Appendix K – Service Information**

### The philosophy of the service

There was a large number of staff at the unit, including psychiatrists, psychologists, nurses, social workers, family therapists, occupational therapists and teachers. There were several members of agency staff on shift at any one time and the team changed frequently.

The service as a whole tended to take a medicalised approach to managing acute child and adolescent mental health difficulties, with an emphasis on defining diagnosis and finding appropriate psychiatric medication. There was also a large focus on smooth transition back into the community and the service took care to ensure that discharges were gradual and phased. A priority for multi-disciplinary discussions was risk management and maintaining a young person's safety whilst on the ward.

Research was highly valued and there were often several research projects underway at any one time within the unit. Members of the clinical team were encouraged to carry out their own research, or supervise others to do so, in addition to their other duties. Theory-practice links were often talked about explicitly in team meetings and the service appeared forward thinking and keen to embrace new research.

### The nature of interventions and support provided

The primary role of the service was to provide a through period of assessment, particularly in cases where there was felt to be diagnostic uncertainty. All adolescents were offered individual therapy sessions, which tended to be

informed by CBT and DBT approaches. Many adolescents were also seen for family therapy alongside their family members. There were few group interventions available, although there were a number of activities that took place on the ward, including a full time educational provision and leisure activities. Adolescents were allocated one keyworker per shift, although due to the large numbers of staff young people often had several different keyworkers rather than a team of two or three core clinicians.

#### Opportunities for parents to attend meetings

Parents and carers were encouraged to attend their child's weekly ward rounds in order to gain an update on the adolescent's care from members of the clinical team. This tended to be the main reliable source of information for parents. They were also invited along to any CPA meetings throughout the duration of the adolescent's inpatient admission, as well as meetings to discuss changes to the adolescent's leave arrangements and for discharge planning.

For those whose children had lengthier stays in hospital, parents and carers were offered the opportunity to attend family therapy alongside their adolescent. There was also a rolling group DBT course that ran frequently and was designed for both parents and their child to attend together.

Clinicians however did not routinely meet with parents without their child being present. They would sometimes be offered individual sessions with a clinical psychologist when deemed necessary, usually within the context of high levels of parental distress.