Chaos, Conflict and Distance:
A Narrative Analysis of the Experiences of Parents of Children in Inpatient Child and Adolescent Mental Health Services

Suzanna C. Greally

A thesis submitted for the degree of Doctorate in Clinical Psychology (DClinPsych)

School of Health and Social Care
University of Essex

March 2023

Acknowledgements

To my parents: thank you for believing in me and for your unwavering support as I have worked towards becoming a Clinical Psychologist. I could not have done this without you, and I am so grateful to have had your encouragement and support.

To Ben: thank you for celebrating every doctorate milestone with me. There is nobody I would have rather shared this experience with.

To Associate Professor Jeppe Oute and Professor Susan McPherson, who have been excellent supervisors: thank you for the thought-provoking, inspiring discussions.

Finally, to the fifteen parents who generously, honestly, and movingly shared their stories with me: thank you. I hope you feel that this thesis fairly represents your stories. I wish you and your families the best.

Table of Contents

List of Tables

List of Figures

Abstract

The prevalence of mental health difficulties among children and adolescents appears to be increasing. In the UK, young people receive treatment for mental health difficulties in child and adolescent mental health services (CAMHS), and those requiring the most intensive treatment receive this in inpatient CAMHS.

Research into family caregiving in the context of mental health has favoured spousal relationships and other adult-to-adult relationships. Literature on parents caring for children has concentrated on physical illnesses or disabilities. Research has also favoured objective aspects of caregiver burden, with less attention given to subjective, psychological experiences.

A qualitative, systematic review of the experiences of parents caring for children of any age with mental illnesses indicated that no research had explored the experiences of parents who have a child in inpatient CAMHS. As such, the aim of this research was to explore the subjective experiences of parents of children who are receiving treatment in inpatient CAMHS.

In-depth interviews were conducted with fifteen parents of children in inpatient CAMHS wards in England. A critical realist ontology was maintained, and the research was conducted within a contextualist epistemology. A narrative analysis was conducted, using Frank’s (1995/2013) narrative types (chaos, restitution, quest) as listening devices.

Narratives of restitution and quest were not found to represent the parents’ stories, so two new narrative types were proposed. The three narrative types therefore comprised: narratives of chaos, narratives of conflict, and narratives of distance. These reflected parents’ responses to distressing situations and emotions, and their attempts to make sense of those experiences.

The results are critically considered in relation to narrative theory and existing literature on caregiving, and the implications of the research are discussed. The narrative types may be used by clinicians working with parents to better understand their experiences and to tailor therapeutic interventions to support them.

Introduction

This chapter presents an introduction to the research. It begins by situating the research within the global context of the increasing prevalence of child and adolescent mental health difficulties. This is considered in light of the different ways in which mental health difficulties are conceptualised; medical, cognitive-behavioural, and systemic models are considered in turn. The current provision of NHS child and adolescent mental health services (CAMHS) in the UK is then described in order to position the research within its national context. Subsequently, the focus moves away from the child and towards the parents, describing key theories and studies concerning parent/caregiver distress in the context of physical and mental illnesses. To provide an overview of the existing research in the area, the remainder of the chapter presents a qualitative systematic review which explores the experiences of parents caring for children (of any age) with mental illnesses. This leads onto the rationale for the current research, and the aim of the research is stated.

Child and Adolescent Mental Health

Children and adolescents constitute almost a quarter of the global population, but there is a shortage of data on child and adolescent mental illnesses and poor data on the global prevalence of mental illnesses (Erskine et al., 2017). However, estimates suggest that up to half of all mental illnesses start before the age of 14 years (WHO, 2014), and a meta-analysis by Polanczyk et al. (2015), which looked at the prevalence of mental illnesses across 27 countries, found a 13.4% global prevalence among children and adolescents. Overall, emotional distress in young people is a significant cause for concern; in the UK in 2020, intentional self-harm (including suicide) was the leading cause of death for young people aged 5 to 19 years old (Cornish & Owen-Williams, 2021), and worldwide, mental illness is one of the leading causes of burden when prevalence, disability and mortality are taken into consideration (GBD 2019 Mental Disorders Collaborators, 2022).

Mental health problems amongst young people appear to be increasing. Trends over time can be identified for children aged 5 to 15 years in the UK: there has been an increase in the prevalence of disorders since data was first collected by NHS Digital in 1999 (a rise from 9.7% in 1999 to 11.2% in 2017; Sadler et al., 2018). This upward trend has continued; more recent data published by NHS Digital on children aged 7 to 16 years indicated that 18.0% had a “probable mental disorder” in 2022 (Newlove-Delgado et al., 2022).

It is unclear whether the COVID-19 pandemic exacerbated mental health difficulties amongst young people. When the period of April to June of 2020 was compared to April to June of 2021, a 134% increase in referrals to CAMHS was identified (Royal College of Psychiatrists, 2021). However, while the disruption caused by the COVID-19 pandemic may have contributed to an increase in mental health problems and referrals to CAMHS, data suggests that these increases were emerging prior to the pandemic. Based on data obtained by the Education Policy Institute, there was already a 26% increase in the number of referrals to CAMHS across a five-year period, between 2013/14 - 2017/18 (Whitney & Hutchinson, 2018), suggesting that there was a general trend of increasing referrals prior to the pandemic. Furthermore, data suggests that rates of mental disorder among children aged 7 to 16 years were stable during the pandemic between 2020 and 2022 (Newlove-Delgado et al., 2022). For some children, the changes caused by the pandemic were protective: some researchers have found that young people who had mental health difficulties prior to the pandemic experienced a reduction in symptoms during the pandemic (Knowles et al., 2022; Widnall et al., 2020). Waite et al. (2021) also found a slight decrease in emotional symptoms among healthy adolescents (although not pre-adolescent children) during the first national lockdown between March and May 2020. However, the authors noted that this finding is difficult to interpret given the lack of pre-pandemic data.

While the impact of COVID-19 on the mental health of young people is unclear, there has evidently been an increase in demand for NHS CAMHS over recent years. The mental health sector has expanded over the last ten years to address this, with the CAMHS workforce increasing by 41% from 2018 to 2021 (NHS Benchmarking Network, 2021). Despite this, in January 2021, the Children's Commissioner for England stated that services were still "nowhere near meeting the level of need" (De Souza, 2021).

It is important to consider what impact an increase in service provision has on the population. Jorm et al. (2017) investigated whether the increase in mental healthcare provision in four English-speaking, industrialised countries (England, USA, Canada, Australia) had decreased the prevalence of mental illnesses between 1990-2015. Despite a significant increase in the use of antidepressants, and "possible" increase in the use of talking therapies, there was no evidence of reduction in mental illnesses. Instead, data collected more recently suggests a dramatic increase in mental health problems, with an additional 500,000 young people in the UK experiencing mental health problems in 2022 compared to 2017 (Peytrignet et al., 2022).

Much of the data presented above would suggest that many more young people are becoming "mentally ill" each year. The impact of the COVID-19 pandemic on young people and families should be held in mind, but the relationship is unclear, and findings are inconsistent (Waite et al., 2021). There are a number of other possible reasons as to why mental illnesses amongst young people appear to be increasing, and this is particularly relevant given the earlier presentation of data that suggests that mental illnesses were on the rise before the pandemic. Rose (2006) proposed five hypotheses that might account for the "expansion" of mental illnesses, still applicable today: a) that there is, actually, more mental illness now than before; b) that there is better awareness and recognition of mental illness; c) that psychiatrists are passionate about their moral cause of identifying and treating distress; d) that pharmaceutical companies distort our perception and treatment of mental illness for profit; e) that human discontent is reshaped and moulded into psychiatric terms. These hypotheses highlight the importance of thinking critically about the model of mental illness and how it is conceptualised.

Conceptualising Childhood Distress

The dominant way in which childhood distress is conceptualised within healthcare is based on the medical model. Brinkmann (2016) called this the "diagnostic culture"; within a medical model of distress, models of physical disease are applied to behavioural and emotional difficulties, producing diagnoses. This constitutes the medicalisation of distress, which produces the language of "illness" and "treatment" (Conrad, 1975, as cited in Busfield, 2017). Diagnoses locate the sources of problems within individuals (Cooper, 2014/2018) rather than emphasising the role of social, systemic, and other contextual factors in contributing to distress (The British Psychological Society, 2011). Despite the poor validity (Kinderman et al., 2013) and reliability (Freedman et al., 2013) of psychiatric diagnoses, this remains the dominant way of conceptualising distress.

The Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) is the dominant classification system for psychiatric disorders. It has been widely criticised, and both the United Nations Human Rights Council and The British Psychological Society have argued that a "paradigm shift" in relation to psychiatric diagnoses is needed (Human Rights Council, 2017; The British Psychological Society, 2013). Over the last 40 years, there has been a dramatic increase in the number of disorders included in the DSM (Davies, 2022, p.6); this is considered to be one of the "most controversial changes" to the manual (Cooper, 2014/2018). The United Nations Human Rights Council commented that the expansion of parameters for diagnoses in both the DSM and International Classification of Diseases (ICD; World Health Organisation, 2019) is occurring "without a solid scientific basis" (Human Rights Council, 2017).

It has also been argued that the increasing use of diagnoses removes issues from the political, moral, and social spheres (Cooper, 2014/2018). For instance, what is now known as Attention-Deficit/Hyperactivity Disorder (ADHD) was first included in the DSM-II as "hyperkinetic reaction of childhood" in 1968 (Lange et al., 2010). Over at least the last three decades, the diagnosing of ADHD has become increasingly widespread, and is considered by some to be amongst the most controversial of diagnoses (Rose, 2006). The increased diagnosing of ADHD is thought to be connected to an increased willingness in teachers to identify students eligible for special educational provision (Olfson et al., 2003). However, Cooper (2014/2018) highlights how prior to the mainstream diagnosing of ADHD, parents, teachers, and professionals would have considered many other reasons for a child's behaviour, including the individual differences of children, styles of parenting, and the education system. Instead, these explanations are now overlooked, and the cause of disruption is located inside the child's brain, absolving children, parents, and teachers from blame (Cooper, 2014/2018). In other words, behaviour that may once have been considered normal is instead considered symptomatic of a disorder, requiring treatment. Importantly, it has also become easier to obtain diagnoses as thresholds have lowered, including for ADHD (Voort et al., 2014), but also for other conditions such as Autism Spectrum Disorder (Wing & Potter, 2002), and Major Depressive Disorder, for which a bereavement is no longer an exclusion clause (Busfield, 2017). The changes in the way disorders are classified make it easier for a young person to receive a diagnosis of mental illness than ever before, perhaps explaining, in part, the increased prevalence of diagnoses.

In contrast to the medical model, the cognitive-behavioural model is a popular way of conceptualising distress in mental health policy and amongst psychologists. Formulation, rather than diagnosis, is a principal component (Beck & Beck, 2011), and distress is understood to emerge as a consequence of a person's thoughts and behaviours. Maintenance formulations within the cognitive-behavioural model depict how a person's thoughts, emotions, behaviours, and physiological responses are connected; this therefore provides a starting point for intervening therapeutically as a change in one aspect of the maintenance cycle is believed to create changes in others. Unlike the medical model, this approach allows psychologists to emphasise how a young person's difficulties make sense in light of their thinking styles and behaviours. However, the emphasis in both the medical and cognitive-behavioural model is on the individual, with little consideration given to other social, political, or systemic influences, meaning that distress is still individualised and depoliticised.

A third and final model is considered here, although there are others. The systemic model allows for far more attention to the relational experiences within a family or a society than do the aforementioned models. In contrast to the medical model, the language of "symptoms" and "disorder" is dropped as difficulties are conceptualised as manifestations of the problems between people or between systems, rather than residing within individuals (Johnstone & Dallos, 2014 p.68). Moreover, in contrast to the cognitive-behavioural model, the systemic model encourages practitioners to consider how family systems will work to maintain a state of equilibrium and balance (homeostasis), meaning that problematic behaviours or interactions may actually be serving to maintain the family's homeostasis (Hoffman, 1981). These problematic behaviours can therefore be considered indicative of difficulties within a family.

Kazak (1989) was the first to argue that family systems and social-ecological models could be applied by clinical psychologists to understand families of children with chronic illnesses. She emphasised that chronic illness impacts the whole family system and therefore moved away from the idea that pathologies are held within individuals. She argued instead that family systems theory could helpfully be used to demonstrate how “a chronic illness in a child is therefore not contained within the child”. This argument neatly illustrates the importance of considering childhood distress within the family system.

Many other aspects of systemic theory can be applied to aid an understanding of familial experiences in the context of chronic illness in childhood. The family life cycle (Carter & McGoldrick, 1988), for example, allows for consideration of how the onset of illness at a transitional point, such as the transition from childhood to adolescence, may be particularly destabilising for a family. Carter and McGoldrick (1988) also highlighted how distress often emerges while a transition between life cycle stages is being negotiated, making it important to consider why a problem may have presented at a particular time.

In this thesis, a systemic understanding of childhood distress is held, with an appreciation of how the emotional symptoms that present within a young person can be viewed as a manifestation of the emotional symptoms of their family (Haefner, 2014). The relevance of this for this thesis is that the focus is on the experiences of parents of patients, rather than the patients themselves, and a wider lens is therefore required.

At this point, a comment on terminology is also needed. It has been noted that when writing about mental health, the language used to describe those who have diagnoses has become a politicised issue; Cooper (2014/2018) writes, for instance, about the different terms used to describe people in mental health services (“patient”, “service user”, “client”, “survivor”). Similarly, it should be acknowledged that despite efforts within clinical psychology to consider childhood distress within a system and context, there remains tension between this approach and the medical model. This tension is perhaps perpetuated by the organisation of NHS services, which are set up in such a way that a medical formulation of distress is needed in order to access services, as children receive treatment for “diagnoses” in NHS CAMHS. However, the comments by Walker (2006), in his paper on the social construction of mental illness, were helpful: he suggested that one rationale for diagnoses is that they provide “a shorthand way of communicating with other professionals”. Families, too, are known to appreciate the provision of a shared language to describe their experience, with Karp (2002, p.27) noting that the medical framing of distress “clarifies the circumstance of caregivers”. Therefore, in this thesis, the “shorthand” of medical diagnoses (Walker, 2006) and the term “mental illness” will be adopted. This is necessary not only to facilitate comprehension for the reader but also to remain respectful of the children who have received diagnoses, of the families who may be affected by this research, and of the NHS services in which children receive support.

CAMHS Provision in England

Child and adolescent mental health services have received an increase in attention over the last decade. A national call for improvement in children's services has occurred, perhaps uncoincidentally, in conjunction with increased pathologizing of children's difficulties.

Over the last decade, the NHS commissioning board, NHS England, has published a number of planning documents which outline priorities for healthcare funding and distribution of resources. The Five Year Forward View (NHS England, 2014) outlined plans to improve provision of mental health services for young people, aiming to provide support to 70,000 more young people by 2020/2021. The Chief Executive Officer of NHS England at the time, Simon Stevens, acknowledged the "welcome national recognition of the need to make dramatic improvements", particularly in child and adolescent mental health services (Department of Health, 2015).

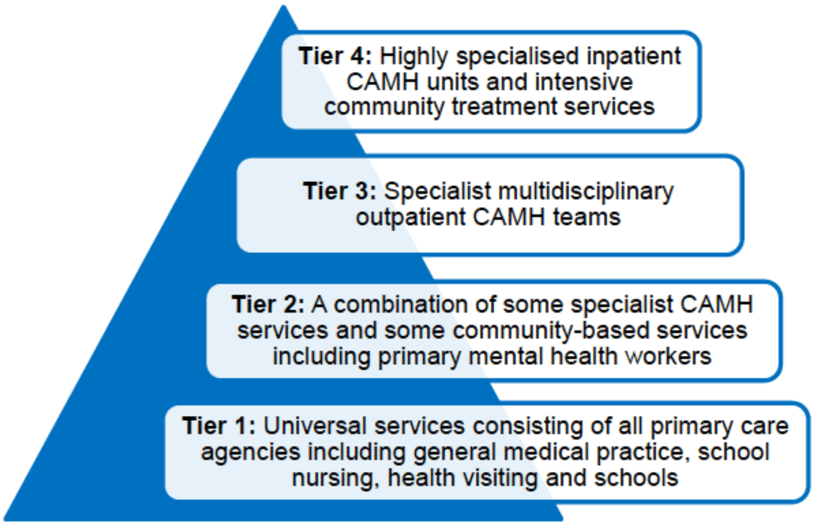
Despite increased spending in mental health services, many targets were not met. In 2019, young people were waiting an average of two months for treatment, considerably longer than the four-week standard set out in the government's green paper (Crenna-Jennings & Hutchinson, 2020). Similarly, there had been no proportional improvement in the number of young people being accepted into treatment, with approximately 25% continuing to be rejected, often because their difficulties did not map neatly onto a diagnostic category, deemed either too complex or not serious enough (Crenna-Jennings & Hutchinson, 2020).

In the NHS Long Term Plan (2019) there was a further commitment to significant investment in, and expansion of, child and adolescent mental health services, meaning that funding for CAMHS would grow faster than both the total spending in mental health and the NHS funding overall. At the time of the publication of the Long Term Plan (NHS, 2019), two thirds of young people with a diagnosable mental illness were still not receiving treatment (Education Policy Institute, 2019). Subsequently, the NHS Implementation Plan for 2019/20–2023/24 restated and reaffirmed the commitments outlined in the Five Year Forward View and further defined plans to provide support to an additional 345,000 young people aged 0-25 years by 2023/24.

While CAMH services were expanding, many were also undergoing changes in service design. Until recently, the dominant model of service provision for child and adolescent mental health services was the four-tier model, developed in 1995 (NHS Health Advisory Service, 1995). This model (presented in Figure 1) made distinctions between four levels of support that could be accessed by young people. Those requiring low-level input could access Tier 1 services which offered non-specialist support for common childhood difficulties such as sleep disturbance. Young people requiring more support would receive help in Tiers 2, 3, or 4. Those accessing Tier 4 services had the most severe and enduring difficulties and were requiring inpatient care or intensive outpatient support.

Figure 1

CAMHS Tier System



Note. Image retrieved from Scottish Government (2017). In the public domain.

At the time of the publication of the Long Term Plan (NHS, 2019), however, a new service model, Thrive, was being implemented across the under-18 population. The Thrive framework (Figure 2) was developed by Wolpert et al. (2014) and offered as an alternative to the four-tier model. In 2019, over half (62%) of children in England were living in localities using the Thrive framework (i-THRIVE, 2019).

Figure 2

Thrive Framework

Note. Image retrieved from Wolpert et al. (2019). In the public domain.

The developers of Thrive outline that this new model organises young people into "needs-based groupings" based on the support and resources they require. They contrast this to the Tier model which places emphasis instead on increasing severity (Wolpert et al., 2015). The authors anticipated that 80-90% of young people would fall into the "thriving" group at any one time; these are the children who experience distressing events but draw on their environment and care from those around them to continue to thrive. Those in the "getting advice" group will be provided with education in order to allow them to adjust to their life circumstances, and may include those with mild difficulties or young people with chronic difficulties who are "on the road to recovery" (Wolpert et al., 2015). The "getting help" group includes young people who would benefit from a time-limited, evidence-based treatment. The "getting more help" group loosely maps onto Tier 4 in the previous model; these young people benefit from either extensive outpatient care or an inpatient admission. The fifth and final grouping, "getting risk support", comprises young people who have ongoing difficulties and high levels of risk but have not benefitted from treatment.

While services transition from Tiers to the Thrive model, there is a degree of overlap, and some service specifications continue to refer to the Tier model. At the time of writing, the most recent service specification still refers to Tier 4 (NHS, 2018) and sets out the criteria for admission, which include: (a) a primary diagnosis of mental illness; (b) secure and complex needs that cannot be safely managed within Tier 3 CAMHS; (c) child aged between 13 and their 18th birthday. Exclusion criteria include a moderate or severe learning disability, or a primary diagnosis of substance misuse or conduct disorder. Other exclusion criteria are based on decisions about the appropriateness of an admission, such as in cases where severe autism might mean that a child would receive more appropriate care in a different, more specialist, service.

Young people require a referral from Tier 3 to enter a Tier 4 service. The specification outlines that Tier 4 services should aim to discharge young people back to Tier 3 CAMHS as soon as this can be done safely; discharge planning should start before admission, or at the time of admission, and involve decisions about what changes would need to occur to allow the young person to be discharged safely and stepped down to Tier 3.

The relevance of this information is as follows: whether following a Tier model, or a Thrive framework, young people receive different support based on their needs. It is evident that there remains a group of young people who require the most extensive and intensive support – this is typically those in inpatient care. The majority of these children are cared for by their parents prior to their admission and return home to the care of their parents when discharged from the inpatient wards. These parents, now assuming the role of caregiver, bear the main burden of their child's care and treatment (Jacoby et al., 2021). The remainder of this chapter thus incorporates literature on caregiving and considers the impact on parents and family caregivers of caring for those with chronic physical and mental illnesses.

Caregiving

An unpaid carer is a person who cares for a family member or friend who would be otherwise unable to cope (for example, due to illness or disability), and it is likely that everyone will take on some degree of caring responsibilities at some point in their life (NHS England, 2020). In 2020, seven per cent of the UK population, or 4.5 million people, were providing unpaid care to a relative (Department for Work and Pensions, 2021). The main recipients of this unpaid, informal care were elderly parents, with those aged 85 and older the most likely to receive care, and 55 to 64-year-olds the most likely group to be providing care. Of all those receiving care, 33% were parents, followed by spouses (17%), and children (12%) (Department for Work and Pensions, 2021).

In the UK, an important piece of legislation relating to caregiving is the Care Act (2014), which outlines the responsibilities of local authorities in assessing need and providing publicly funded care to those who require it. Under this legislation, informal carers, such as family members, have the right to a statutory assessment of their needs. For those deemed eligible for support, this might be granted in terms of financial assistance for transport, help with housework, structural changes to the home, provision of equipment, or care provision by paid carers, among other things.

Parenting and Childhood Illness

With regards to caring for a child who is unwell, and thus taking on the role of carer in addition to parent, there are gaps in the body of research. For instance, research into the experiences of parents of children with mental illnesses is limited, particularly regarding those whose children access intensive mental health treatment (Preyde et al., 2015). There is, however, a larger body of research concerning parents of children with chronic physical illnesses or learning disabilities, and, while different to mental illnesses, this can help to inform a meaningful understanding of parental experiences of caring for a child with additional needs.

Much of the research involving parents of children with chronic illnesses has highlighted the increased stress experienced by these parents. A meta-analysis by Cousino and Hazen (2013) found that parents of children with chronic illnesses experienced significantly higher levels of parental stress than parents of healthy children. There also appeared to be illness-related factors that mediated parental stress. For parents of children with cancer, activity limitations caused by treatment were associated with poorer parental quality of life, and other illness-related factors associated with higher levels of parental stress included sleep-disordered breathing in children with asthma and poor adherence to treatment in children with cystic fibrosis, among other conditions. The authors also hypothesised that higher levels of parental stress during times of frequent or intense pain in their child were associated with parental feelings of helplessness during the child’s pain. Other studies have found that severity of illness is not associated with parental stress, such as Uzark and Jones’ (2003) research involving parents of children aged two to twelve years with heart disease. In this study, the age of the child was positively correlated with parental stress, with parents of older children experiencing higher levels of stress. This is meaningful in light of systemic ideas such as the family life cycle (Carter & McGoldrick, 1988), which suggests that transitions between life stages (such as childhood to adolescence) may be destabilising for a family system. Finally, a qualitative meta-synthesis by Coffey (2006) described parents of children with physical illnesses as “living worried” and waiting for the worst to happen, highlighting the pervasive nature of the stress experienced by these parents.

Given the distress experienced by parents of children with chronic illnesses, some require individual support to help them cope. The NHS website signposts parents to various charitable organisations and reminds parents that they may be eligible for carers' support (NHS, 2021). Some research has evaluated the effectiveness of psychological interventions for parents of chronically ill children. For example, one systematic review by Law et al. (2019) reviewed the effectiveness of psychological therapies for parents of children with a chronic illness, including traumatic brain injury, cancer, asthma, and pain. The authors concluded that interventions may have some benefits for parents, including a reduction in symptoms of anxiety and depression in parents of children with cancer and parents of children with chronic pain. The authors also noted, however, that the quality of evidence in the studies was low and that many outcomes could not be evaluated due to insufficient data.

Research into parental experiences of caring for a child with a learning disability is also relevant. A review of the literature by Willingham-Storr (2014) identified that the burden of caring for a child with a learning disability significantly impacted on parents' ability to cope. However, the same review also highlighted that parents experienced rewarding and empowering aspects within their parental role. Fathers, for example, felt more committed to their child as a result of the child's learning disability (Carpenter & Towers, 2008), a noteworthy finding in light of other research which, contrastingly, refers to fathers as the "peripheral parent" (Herbert & Carpenter, 1994). Furthermore, a study by Knafl and Zoeller (2000), which compared the experiences of mothers and fathers of children with health conditions such as diabetes and juvenile arthritis, concluded that any differences in parental experiences only highlighted the importance of eliciting views from both mothers and fathers.

Caregiver Distress

This section outlines some of the important theories relating to caregiver distress in the context of illness. The three concepts described below were not developed in the context of mental illness, so the ways in which they have been applied to mental illnesses since are considered. However, as previously mentioned, the experiences of parents of children with mental illnesses have not been adequately studied. An overview of these concepts is therefore important to facilitate an initial understanding of some of the psychological challenges experienced by parents.

Biographical Disruption

Bury (1982), conjectured that the onset of chronic illness was an event of biographical disruption for the sufferer. The author delineated three components of biographical disruption: the disruption of taken-for-granted assumptions and behaviours, a change to biography and self-concept, and mobilisation of resources and support (Bury, 1982). In this paper, he explored the experiences of adult patients aged 25-54 years with rheumatoid arthritis. Since then, biographical disruption has become a meaningful concept in the sociology of health and illness and has been applied to a number of other conditions, including terminal cancer (Reeve et al., 2010), motor neurone disease (Locock et al., 2009), and frailty (Cluley et al., 2021).

Biographical disruption has also been meaningfully applied by Todd and Jones (2005) to the mothers of disabled children. For these parents, the biographically disruptive event is that of becoming the parent of a disabled child, as opposed to the onset of a personal illness. The authors suggested that the disruption may, however, not be experienced until the child transitions into adolescence. They found that the transition from childhood to adolescence posed unique challenges to mothers of children with learning disabilities. They proposed that as a child becomes an adolescent, the mother is also experiencing a transition in her mid-life. Both mother and child are therefore experiencing transition-related identity changes, as well as biological, emotional, and social changes. This is indicative of the significance of adolescence in the family life cycle (Carter & McGoldrick, 1988). As highlighted earlier, transitions between life stages (such as childhood and adolescence) may be particularly destabilising for a family system.

The theory of biographical disruption has not been applied to parents of children with mental illnesses. Given that 48% of mental illnesses have emerged by age 18 (Solmi et al., 2021), the transition to adolescence may be a particularly challenging time for the young person and their parents, with mental health difficulties compounding the disruption experienced by both parties at their respective life stages.

Ambiguous Loss

The theory of ambiguous loss (Boss, 2002) offers another way of conceptualising some of the difficulties experienced by family members when a person is chronically ill. The theory is based on family stress models (Dahl and Boss, 2020) and arose through Boss' interviews with the wives of missing-in-action Navy pilots in 1974 (Pauline & Boss, 2009). Boss (2002) proposed that there are two types of ambiguous loss. The first is when a person is physically absent but remains psychologically present, such as in cases of terrorism whereby a person is presumed dead, but a body has not been found, leaving family members preoccupied with thoughts about the person (Boss, 2002). The second type of ambiguous loss has most notably been described in the context of dementia (Boss, 2011), in which a person, while physically present, is psychologically absent due to their emotional or cognitive difficulties.

Ambiguous loss has since been applied to a wide variety of circumstances, including sudden infant death syndrome (Mahat-Shamir, 2022), transgender youth (Okrey Anderson & McGuire, 2021) and their parents (Coolhart et al., 2018), foster children (Boss, 2018), drug abuse (Mechling et al., 2018), traumatic brain injury (Flores, 2021), the COVID-19 pandemic (Salzman, 2022), and numerous other contexts. In many of these circumstances, such as drug abuse and traumatic brain injury, family members may experience their loved one as physically present while psychologically absent. It is reasonable to hypothesise that parents of children with mental illnesses may experience their child in a similar way when the child remains living at home but appears to be deteriorating psychologically. Contrastingly, one might expect that when a child with a mental illness is removed from the home, such as for an admission into an inpatient ward, parents may experience the ambiguous loss of a physically absent child that remains psychologically present for the worried parent.

Chronic Sorrow

Like biographical disruption, which was applied by Todd and Jones (2005) to the experiences of mothers of disabled children, the concept of chronic sorrow was first presented by Olshansky (1962) to describe the experiences of parents of an intellectually disabled child as they struggled to come to terms with the loss of their “perfect child” (Olshansky, 1962, as cited in Eakes et al., 1998). Like ambiguous loss theory (Boss, 2002), chronic sorrow has since been extensively researched in a variety of circumstances, depicting the long-term, periodic sadness and grief experienced both by people with disabilities or illnesses and their caregivers (Lindgren et al.,1992; Hainsworth et al., 1994; Eakes et al., 1998). Some researchers have amalgamated ambiguous loss theory and chronic sorrow, such as Patrick-Ott and Ladd (2010) in their case study of a family of a child with disabilities.

In a study by Eakes (1995), chronic sorrow was studied in parents of children with mental illnesses. Of the ten parents they interviewed, they found that eight described the grief-related feelings that constitute chronic sorrow. These emotions were connected to the time of initial diagnosis, but were permanent, inescapable, and were “re-experienced at varying levels of intensity”. In this study, the children were all male adults, aged 27 to 46, and had diagnoses of either schizophrenia or bipolar affective disorder. It is less clear how this theory may apply to parents of children with mental illnesses who are under 18 years old.

Caregiving in the Context of Mental Illness

While many researchers have considered the impact on parents of caring for a child with a disability or chronic illness, few have considered the impact of caring for a child with a mental illness. However, mental health related caregiving experiences in other relationships have received more attention and provide a useful starting point for considering the impact of caregiving on the caregiver.

Research into caregiving has brought to light the many difficult experiences of family caregivers, so much so, that the term “caregiver burden” is widely used to describe these negative experiences. This term was first documented in the 1980s and was used to describe the financial, social, emotional, psychological, and physical consequences of caregiving (George & Gwyther, 1986). Since then, caregiver burden has been further understood through the categories of objective and subjective burden. Objective burden denotes the “caregiving labour” (Oute & Huniche, 2017) and objective changes to, for instance, routine, work, and hobbies (Kumar & Gupta, 2014). Subjective burden encompasses the distress and other emotional consequences experienced by the caregiver and is thought to be the most important factor affecting caregiver wellbeing (del-Pino-Casado et al., 2021).

Relevant to the literature on caregiving is a consideration of the current provision of social care in the UK. Expenditure on social care has decreased over time; when adjusted for inflation, spending on social care in 2015/16 was lower than ten years prior in 2005/06 (Office for National Statistics, 2017). Furthermore, despite significant extra funding provided during (and due to) the COVID-19 pandemic, after adjusting for the increase in population over recent years it emerges that spending per person actually decreased from £593 per annum in 2010/11 to £585 in 2020/21 (The King’s Fund, 2022).

With a decrease in social care expenditure, individuals often have little choice other than to take on more caregiving responsibilities within their families. Research into the responsibilisation of caregivers in the UK and Denmark (McPherson & Oute, 2021) highlights how depression guidelines reflect an objective of relieving the burden of illness on the state through the responsibilisation of family caregivers, with policies and guidelines developed without making use of the existing qualitative literature on family life in the context of depression, and with a whitewashing of the burden experienced by these families.

Furthermore, individualisation of difficulties and responsibilisation of caregivers also means that the interconnectedness of families, the role of family issues in understanding difficulties, and the limitations of individualised approaches are not considered (McPherson & Oute, 2021).

There are significant consequences to the wellbeing of those living with and/or providing care to family members. In a study by Ahlstrom et al. (2009), experiences of family members living with an adult with depression were elicited through group narrative interviews with families. Participants described experiencing instability in their everyday lives and being forced to relinquish attempts at controlling their lives – ordinary activities became difficult, and they had little support from others. Similarly, research into caregiving for family members with dementia has demonstrated that all aspects of carers' lives are negatively impacted by their caring responsibilities. Early on in research into caregiver burden, Kapust (1982) described the experience of living with a family member with dementia as an "ongoing funeral". A quantitative study by Papastavrou et al. (2007) found that 65% of caregivers of people with dementia exhibited symptoms of depression, with the authors concluding that the behaviour of the patient was predictive of both burden and depression in the caregiver. Furthermore, a systematic review of caregiver burden trajectory in family caregivers of people with dementia found that the main trajectory was an increase in burden over time (Van den Kieboom et al., 2020). Higher incidence of neurological and behavioural symptoms over time was also associated with higher caregiver burden. The review further highlighted that of all caregiving relationships, those caring for a spouse were particularly vulnerable to increased burden as the dementia progressed.

Spousal relationships within mental health caregiving have been studied in the context of other illnesses, including depression. Oute and Huniche (2017) proposed that the objective and subjective caregiver burden of adults caring for a spouse with depression is highly dependent on the gendered distribution of roles and responsibilities, which is disrupted when one partner becomes depressed. The significance of the impact of caring for a partner with depression is such that it has been termed a "couples' disease" (Priestley et al., 2018). These authors noted that the strong sense of loyalty within a couple relationship may mean that the caregiver finds it more difficult to create distance between themselves and their partner, and they contrasted this to the experiences of caregiving within other adult-to-adult relationships. However, it can also be noted that caregiving within a couple relationship will tend to occur within a cohabiting relationship, which is less likely to be the case in instances of adults caring for a friend, for an adult sibling, or for a parent. In support of this, Van den Kieboom et al. (2020) hypothesised that the association between spousal relationship and increased caregiver burden over time (within the context of dementia) was due to the fact that most couples are cohabiting.

Given what has already been highlighted about the prevalence of mental illnesses among children and young people, it is surprising that there appears to be very little research into parental experiences of caring for children with mental illnesses. In light of the research that has been presented thus far, illustrating what is known about parental stress and burden when caring for a child with a chronic illness or disability as well as the relationship between behavioural symptoms, cohabitation, close relationships, and loyalty on increased burden in the context of adult mental health caregiving, it is important to investigate the experiences of parents caring for children with mental illnesses, in which all of these factors are likely to be highly relevant.

Existing Literature

As outlined previously, while there has been some research into caregiving experiences within mental health, the tendency has been to focus on spousal relationships and other adult-to-adult caregiving experiences. The existing literature on parents caring for children with additional needs has concentrated on physical illnesses and disabilities, rather than mental illnesses. Furthermore, existing research has often favoured studying the objective, rather than subjective, experiences of caregiving, as per definitions of objective and subjective caregiver burden by Kumar and Gupta (2014) and Oute and Huniche (2017). When research on parental caregiving in the context of children with additional needs focuses on objective burden, this produces literature regarding the practical experiences of attempting to access services for a child (e.g. Crouch et al., 2019), the barriers and facilitators to seeking psychological therapies for a child (e.g. Reardon et al., 2017), and views on medication (e.g. Lazaratou et al., 2007). Comparatively less focus is thus given to subjective experiences of burden, defined by Schene (1990) as the “psychological consequences” for the caregiver. Kumar and Gupta (2014) noted that the Zarit Burden Interview (Zarit et al., 1980) is a measure of subjective burden, and, as such, this can be used to facilitate an understanding of the concept of subjective burden. This measure was designed to be used with caregivers of people with dementia; it asks about feelings of stress, loss of control, uncertainty, guilt, discomfort, embarrassment, fear about the future, and the impact on the caregiver’s own health. This delineates some of the subjective aspects of caregiver burden. In this thesis, the concept of subjective experiences is used to denote any emotional or psychological impact on the caregiver.

Given the apparent dearth of research into the subjective experiences of parents who care for a child with a mental illness, a review of the literature is needed in order to provide an overview of the research in this area and synthesise the existing studies. The remainder of this chapter therefore offers a systematic review which explores the subjective experiences of parents caring for children with mental illnesses.

Systematic Review and Meta-Ethnographic Synthesis

Introduction

The remainder of this chapter presents a systematic review and qualitative meta-synthesis of the literature on the experiences of parents of children mental illnesses. While it is noted, earlier in the chapter, that children in inpatient services receive the most intensive and extensive support – suggesting that these parents may face significant challenges – a review is needed to consider, more broadly, the experiences of parents who have children in various treatment settings. The rationale for this is that while there is a small body of research regarding family caregiving experiences more generally, research concerning parents of children with mental illnesses is limited, and the existing literature has not been systematically reviewed or synthesised previously. Given that the body of research on the topic is small, this review will include parents who are caring for children of any age, who are receiving treatment for a mental illness in any treatment setting.

The aim is to synthesise the existing research and the review will be led by the question: what are the subjective experiences of parents who care for a child with a mental illness?

Methods and Methodology

Design

The purpose of qualitative meta-synthesis is to draw together the findings of empirical studies in order to develop and progress existing concepts or theories, so that the results of the synthesis are greater than the sum of its parts (Campbell et al., 2003). Unlike quantitative meta-analysis, which aggregates data in order to detect a relationship between variables, qualitative meta-synthesis involves induction and interpretation (Britten et al., 2002), furthering an understanding of the subject matter and developing theories by translating studies into one another. Gough et al. (2012) made the same distinction between reviews which are aggregative (testing concepts, i.e. meta-analyses) and reviews which are configurative (generating theory, i.e. meta-syntheses), while recognising that there can be some overlap of these methods within a review to a lesser or greater degree.

Approaches to meta-synthesis are varied. Some researchers employ the methods used in thematic analysis (such as line-by-line coding) to the studies to be reviewed, as in thematic synthesis (Thomas & Harden, 2008). Another approach is that of meta-narrative review (Greenhalgh et al., 2005) which allows for the reviewing of studies of similar phenomena which have produced seemingly contradictory results. Meta-ethnographic synthesis, initially purposed for the reviewing of ethnographies, but later deemed appropriate for qualitative research beyond ethnography is another method (Thomas & Harden, 2008; Britten et al., 2002), and Noblit and Hare (1988) have described a seven-stage method of meta-ethnography.

Given the varying approaches, some authors call for transparency and clarity in the reporting of review designs and methods (e.g. Gough et al., 2012), and others have conducted research with the aim of testing the appropriateness of specific review methods. One such feasibility study by Campbell et al. (2003) demonstrated the effective use of a meta-ethnographic approach in synthesising research concerning care in the context of chronic illness, having noted that meta-ethnographic synthesis is thought to be the best-developed method for synthesising qualitative data. The authors concluded that qualitative studies can be synthesised helpfully and successfully by using a meta-ethnographic approach in order to provide novel ways of understanding a phenomenon. They noted that this approach is likely to offer greater insight and theoretical development than other approaches, such as meta-narrative reviews. This suggests that this approach would be appropriate for the present review.

Thomas and Harden (2008) considered some of the differences between a thematic synthesis and meta-ethnographic synthesis. They noted that while there is a degree of overlap between the analytical themes of a thematic synthesis and the third-order interpretations of a meta-ethnographic synthesis, analytical themes are more appropriate when addressing a specific review question, while third-order interpretations are more appropriate when the literature is being explored “in and of itself, with broader, or emergent review questions” (Thomas & Harden, p.9). The question leading the present review is relatively broad, suggesting that a meta-ethnographic synthesis would be an appropriate choice which could lead to conceptual development and thus a richer understanding of the topic. Furthermore, meta-ethnography is used in particular for reviews addressing the meanings or processes of phenomena (Gough et al., 2012), is considered useful for addressing experiences of illness and care (Priestley & McPherson, 2016), and is considered by some to be the most well-developed qualitative synthesis method (e.g. Britten et al., 2002). The interpretivist epistemology underpinning meta-ethnography is also well-aligned with the philosophical positioning of the research.

The information presented above suggested that a meta-ethnographic synthesis would be an appropriate choice for the present review. The seven stages of meta-ethnographic synthesis outlined by Noblit and Hare (1988) were therefore followed in this review: getting started, deciding what is relevant to the initial interest, reading the studies, determining how the studies are related, translating the studies into one another, synthesising translations, and expressing the synthesis.

This review was guided by the PRISMA checklist (Page et al., 2021) and completed in accordance with the transparent reporting of systematic reviews.

Registration

A protocol for the review was prospectively registered on PROSPERO on 14th June 2022 and can be accessed using the ID: CRD42022336049.

Literature Search and Selection

A comprehensive search was planned in order to retrieve all available studies based on the inclusion and exclusion criteria, which were identified before initiating the searches in order to reduce bias (Tawfik et al., 2019). The criteria were as follows:

Inclusion Criteria

1. Study explores subjective parental experiences
2. Study uses qualitative methodology
3. Child has received a diagnosis of a mental illness
4. Full text available in English.

Exclusion Criteria

1. No formal diagnosis or unclear whether a formal diagnosis was required as per the study inclusion criteria
2. Diagnosis of Learning Disability, Attention-Deficit/Hyperactivity Disorder, or Autism Spectrum Disorder without co-morbid mental illness
3. Study focused on objective experiences or specific aspects of care (e.g. medication; parental beliefs of cause of illness; barriers/facilitators to accessing treatment; transition to adult care; professionals' ways of working with parents; help-seeking; receiving diagnosis; evaluation of specific treatment programme) rather than subjective experiences
4. Interviews conducted with non-primary caregiver family members (e.g. sibling; spouse) rendering it impossible to separate the results and conclusions of parental interviews from other family members.

Data Sources and Electronic Search Strategy

Four databases were searched using the following search strategies during June/July 2022, whereby *MeSH Terms* denotes Medical Subject Headings, *MH* searches both major and minor headings for the exact CINAHL subject heading, “+” sign denotes that the subject heading has been exploded, *AB* denotes Abstract, and *SU* denotes Subject Terms. The search strategies were as follows:

1. PubMed (searched on 22nd June 2022)
   ("Child"[MeSH Terms] OR "Adolescent"[MeSH Terms]) AND "Mental Disorders"[MeSH Terms] AND ("Parents"[MeSH Terms] OR "Caregivers"[MeSH Terms]) AND "Qualitative Research"[MeSH Terms]
2. CINAHL Ultimate (searched on 26th July 2022)
   (MH "Child+" OR MH "Adolescence+") AND (MH "Mental Disorders+") AND (MH "Parents+") AND (MH "Qualitative Studies+"). Limiter: English
3. APA PsycInfo (searched on 30th July 2022)
   AB qualitative AND AB (child* OR adolescen*) AND AB (parent* OR care*) AND SU mental disorders
4. MedLine Ultimate (searched on 30th July 2022)
   AB qualitative AND AB (child* OR adolescen*) AND AB (parent* OR care*) AND SU mental disorders

Study Screening Methods

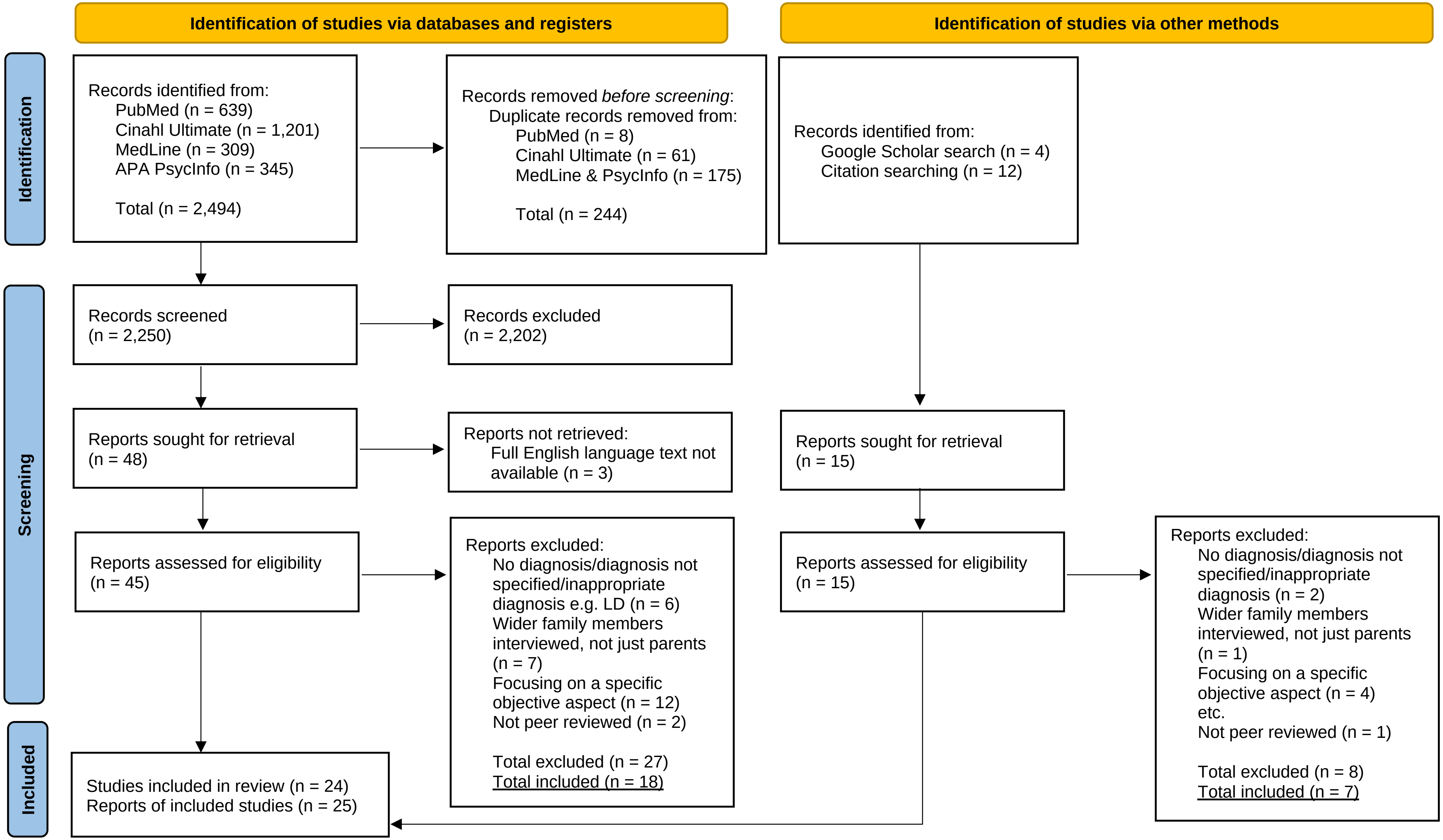
The records derived from each of the four database searches were exported to EndNote to carry out the initial screening process. An automation tool on EndNote was first used to remove duplicates; titles and abstracts of the remaining records were then reviewed against the eligibility criteria and records that did not meet the criteria were excluded at this point. The reports of the remaining records were retrieved, and the author again reviewed these against the eligibility criteria, noting the reasons for exclusion of reports at this stage. The 18 remaining reports were included in the review (Armitage et al., 2020; Bai et al., 2020; Darmi et al., 2017; Donnelly, 2001; Gok & Duyan, 2020; Harden 2005a; Harden 2005b; Kanungpiarn et al., 2021; McCormack & McCann, 2015; Mohr & Regan-Kubinski, 2001; Piuva & Brodin, 2020; Poonnotok et al., 2016; Raymond et al., 2017; Sarrió-Colasa et al., 2022; Stapley et al., 2016; Svensson et al., 2013; Thomson et al., 2014; Wade, 2006).

As it is unlikely that electronic databases are comprehensive (Siddaway et al., 2019), additional literature was then identified through a Google Scholar search, and forward and backward reference searching was conducted using the reference lists of the 18 included studies as well as the studies identified through Google Scholar. Reports were retrieved, assessed for eligibility and reasons for exclusion were noted. This process yielded an additional seven studies which were included in the review (Johansson et al., 2010; Johansson et al., 2012; McAuliffe et al., 2014; O'Hare et al., 2017; Pejlert, 2001; Tuck et al., 1997; Wiens & Daniluk, 2009). A total of 25 reports were therefore included in the review.

The detailed study selection process is displayed in the PRISMA diagram (Figure 3). The screening and study selection processes were carried out independently by the author.

Figure 3

PRISMA Diagram



Appraisal

Quality Assessment

Currently, there is no consensus on whether or not quality appraisal should be undertaken during the process of a qualitative systematic review, nor is there any one agreed method of appraising the quality of qualitative research (Dixon-Woods et al., 2006). Authors of qualitative meta-syntheses who do conduct quality appraisals have differing opinions on whether studies should be excluded on the basis of quality, with some choosing to exclude papers deemed low quality, while others include all papers regardless of quality. Among those who choose to include all papers, there is yet more debate on whether studies should be weighted differently in analysis based on their quality.

Noblit and Hare (1988) suggested that study quality is actually assessed during the process of the synthesis, and as such, some authors argue that the question of whether or not to appraise quality is a “moot point” (Campbell et al., 2003). Campbell et al. (2003) also point out, however, that Noblit and Hare’s (1988) ideology came before much of the discussion on quality appraisal and suggest that quality appraisal can instead be considered the first stage of the synthesis. In their 2003 paper, the authors chose to eliminate studies of lower quality based on the results of the appraisal.

Despite debate on the matter, many still consider quality appraisal to be an essential part of the synthesis (e.g. Carroll et al., 2013). Therefore, the Critical Appraisal Skills Programme tool for qualitative research (CASP, 2018) was used to appraise the studies included in this review. This appraisal was carried out independently by the author. While the use of checklists to appraise quality has been a matter of debate (Dixon-Woods et al., 2006), the CASP was developed for use within health research and is recommended by the Cochrane Qualitative and Implementation Methods Group. However, as it is not clear whether or how lower quality studies should be excluded (Dixon-Woods et al., 2006), all eligible studies were included in the review, regardless of quality. The CASP tool comprises nine questions which obtain Yes/No responses, and a tenth question which offers the assessor the opportunity to narratively appraise the value of the research.

A tabulated version of the quality appraisal for the studies included in this review can be found in Appendix A. Although the studies were of good quality overall, a number of limitations were highlighted by the quality appraisal. These are critically considered below.

A clear statement of the aims of the research was provided in all studies. All studies also appropriately used qualitative methodology to address their research question(s) and had appropriate research designs. Appropriate recruitment strategies and methods of data collection were also used in all studies. However, in a number of studies, there was little or no documentation of critical appraisal or reflexivity.

Five studies did not provide sufficient information about data analysis to determine how the analysis was undertaken, including how themes were derived from the data. For example, Donnelly (2001) stated that data from the interviews were “synthesised into common themes” with no details provided as to how this was done. The author described conducting a “unique method of data analysis”, but in the absence of a description of how this analysis was carried out, it is not possible for other researchers to attempt to analyse interviews in a similar way. In another study (Gok & Duyan, 2020), the authors reported to have carried out thematic analysis but did not comment on the underlying assumptions underpinning the analysis, meaning it is not possible to determine what type of thematic analysis they undertook. Researchers have been criticised for referring to thematic analysis as though it is a “homogenous entity” in this way (e.g. see Braun & Clarke, 2016, for a critique of Fugard & Pott, 2015). As noted by Clarke and Braun (2017), thematic analysis is not a singular or atheoretical approach, but refers to many different approaches which can be underpinned by different theories.

Eight studies did not describe whether or how the relationship between researcher and participants had been considered, meaning that it was unclear whether researchers had thought critically about their own influence on the research. Several studies commented on themes “emerging” from the data, such as Wiens and Daniluk (2009), Svensson et al. (2013), McCormack and McCann (2015), and O’Hare et al. (2017) – this passive language does not recognise the active role of the researcher in the development of themes (Braun & Clarke, 2006; 2021). Another study (Sarrio-Colasa et al., 2022), which also described themes “emerging” from the data, used this language despite reporting to have followed Braun and Clarke’s (2006) phases of thematic analysis, and referencing this paper in which Braun and Clarke (2006) advised against the use of this passive language. Mohr and Regan-Kubinski (2001) cited measures of trustworthiness that they used to address the validity and credibility of their research. However, in describing their data analysis, they simply stated that transcripts were “analysed for patterns and trends” and “themes […] were negotiated with professional colleagues” without any indication of what method of analysis was used, or how themes were developed. It was also not clear what the “negotiation” of themes involved, and therefore would not be possible for other researchers to attempt to analyse data in a similar way, nor assess whether the author's methods did enhance the trustworthiness or rigour of the study.

Of the studies that did describe how the relationship between researcher and participants had been considered, there were varying degrees of detail. Better quality studies described reflexivity on the part of the researcher, with consideration given to how both the dialogic nature of interviews and characteristics of the interviewers might have affected the information shared by participants and therefore the results of the studies. Harden (2005a), for instance, commented on the "reflexive process" of the analysis, and considered how the participants told stories as well as reconstructed stories through the active process of engaging in their interviews.

One study (Wiens & Daniluk, 2009) did not comment on whether ethical issues were taken into consideration.

Synthesis of Findings

Reading the Studies

The studies were organised chronologically by publication date, and an initial reading of each study was completed, starting with the oldest study (Campbell, 2003). Following this first reading, the studies were printed out and the results and discussion sections were re-read several more times. During these subsequent readings, handwritten annotations were made on the printed copies of the studies. This involved highlighting the themes devised by the original authors, noting down theories that were interesting or novel, paying attention to information directly related to the research question of this review, as well as beginning to note concepts which appeared to be recurring across the different studies.

Determining how the Studies are Related

On a subsequent re-reading of each study, key information relating to methodology was extracted and tabulated, with a new column added for each study. Next, by re-reading the results and discussion sections, and the author's handwritten annotations, it became possible to identify themes or key concepts that were common across the studies. During the process of identifying common concepts, the studies were continuously compared against them. Concepts were excluded and new concepts were added based on this constant comparison. This produced a final set of ten key concepts; these were added to the table.

Translating the Studies Into One Another

The results and discussion sections of each study were then re-read with the key concepts in mind, allowing for data to be extracted relating to each of the key concepts and added to the table. This process therefore made it possible to uncover each concept described in each study, and to determine that the initial concepts (developed by the study authors) in each study were captured by the new key concepts that had been developed and tabulated. In completing the table, the original authors' language was preserved as much as possible in order to remain faithful to the original studies (Britten et al., 2002) and to reduce the likelihood of re-interpreting the original authors' concepts. The final row of the table contained second-order interpretations (Schutz, 1962, as cited in Britten et al., 2002) which go beyond lay-person understanding, and illustrate the principal theories or explanations of each study, often drawing on psychological and social science theory. As in Britten et al.'s (2002) paper, in this row of the table, quotation marks were used to denote use of the authors' own words.

The full table can be found in the appendices; for readability, the table is presented in two parts: a table of methodologies (Appendix B) and a table of key concepts (Appendix C). An illustrative sample is presented in Table 1 below, detailing the key study details (methodology), key concepts, and second order theory for one of the studies.

As the information from each study was entered into a new column in the table, it started to become possible to see how many of the key concepts featured in each study. To better facilitate this cross-comparison of studies by concept, the studies were subsequently placed into a new table (Table 2). This cross-comparison of studies by concept illustrated how the key concepts were distributed across the 25 studies.

Table 1

Illustrative Example of Tabulated Study Details and Concepts

Methods and Concepts	**Darmi et al., 2017**
Key study details	
Aim	To explore parents' lived experience of caring for a child with psychosis
Country	Greece
Health setting	Inpatient and Community
Sample	16 parents (14 mothers, 2 fathers) of adult children aged 20 and above (upper limit not specified)
Mental illness	Psychotic Disorder
Data collection	Interviews
Key Concepts	
Transformation of the loved child	Caring for an intimate stranger. Unable to recognise their son or daughter; a relationship to a frightening stranger
A psychological tsunami of emotions	Pervasive guilt; mixed feelings of fear, anger, and sadness
Realisation	After an acute episode or the official diagnosis, they come to terms with the reality of their son's or daughter's disorder
Getting help	A cruel but necessary treatment
Gendered caregiving	-
Commitment	An unending commitment and a huge burden; self-sacrifice. Trapped in a role of incessant caring
An impossible task	The disorder was described as an unknown, threatening experience with unpredictable outcomes, over which parents had no control
Uncertain future	The thought of the patient's care after their death was a source of anxiety and ongoing concern
Reframing thinking	-
Finding meaning	In search of meaning, making sense of what was happening was important in their striving to rebuild their relationship with their child and assume a new parenting role
Second-order theory	"An anxious-ambivalent parent-child relationship is redefined over the course of the illness trajectory"

Table 2

Cross-Comparison of Studies by Concept

Key Concept	**Transformation of the loved child**	**A psychological tsunami of emotions**	**Realisation**	**Getting help**	**Gendered caregiving**	**Commitment**	**An impossible task**	**Uncertain future**	**Reframing thinking**	**Finding meaning**
Armitage et al., 2020	*	*		*			*	*		
Bai et al., 2020	*	*	*	*			*	*		
Darmi et al., 2017	*	*	*	*		*	*	*		*
Donnelly, 2001	*	*	*	*	*	*	*	*	*	*
Gok & Duyan, 2020		*	*	*	*		*	*	*	*
Harden, 2005a	*	*	*	*		*	*	*	*	
Harden, 2005b	*	*	*	*	*	*	*	*	*	
Johansson, 2010	*	*	*	*		*	*	*	*	*
Johansson, 2012	*	*	*		*	*	*	*		
Kanungpiarn, 2021	*	*	*	*		*	*	*	*	
McAuliffe, 2014	*	*	*	*		*	*	*	*	*
McCormack et al., 2015	*	*		*	*	*		*	*	
Mohr et al., 2001	*	*	*	*		*	*	*		
O'Hare, 2017	*	*	*	*	*	*	*	*		
Pejlert, 2001	*	*	*	*		*	*	*	*	*
Piuva & Brodin 2020	*	*	*	*			*	*	*	*

Key Concept	**Transformation of the loved child**	**A psychological tsunami of emotions**	**Realisation**	**Getting help**	**Gendered caregiving**	**Commitment**	**An impossible task**	**Uncertain future**	**Reframing thinking**	**Finding meaning**
Poonnotok et al., 2016	*	*	*	*	*	*	*	*	*	*
Raymond et al., 2017	*	*	*	*		*	*	*	*	
Sarrio-Colasa et al., 2022	*		*	*	*		*	*		*
Stapley et al., 2016	*	*	*	*		*	*	*		
Svensson et al., 2013	*	*		*	*		*	*	*	
Thomson et al., 2014	*		*	*			*			
Tuck, 1997	*	*	*	*		*	*	*	*	*
Wade, 2006	*	*	*	*		*	*	*	*	*
Wiens & Daniluk, 2009	*	*	*	*		*	*	*	*	*

It is helpful to remain cognisant that the results of meta-ethnographies will differ depending on the author, and, as Dixon-Woods et al. (2006) highlighted in the development of their new approach to meta-ethnography, it is therefore important to ensure that conclusions are grounded in the evidence while maintaining reflexivity during the interpretative work required in synthesising qualitative studies.

To begin synthesising the translations, the tables of the 25 studies were printed out. This facilitated a process by which the key concepts of the studies could be read and compared. It became clear that the studies were not refutational of one another; the commonalities across the studies and their key concepts suggested reciprocal relationships. Moreover, by continuing to re-read the key concepts and translate these across the studies, it was possible to identify a further level of complexity; the ten key concepts were synthesised into five (Table 3) and these five final concepts not only captured the intricacies of the individual studies but offered a line of argument synthesis which described the data overall, going beyond that which was expressed in individual studies.

Table 3

Key Concepts and Synthesised Concepts

Key Concepts	**Final Synthesised Concepts**
Transformation of the loved child A psychological tsunami of emotions	Caring for an intimate stranger
Realisation Getting help	Turning point
Gendered caregiving Commitment An impossible task	Unavoidable role
Uncertain future	Uncertain future
Reframing thinking Finding meaning	Transcendence

Overview of Studies

The 25 studies included in this meta-ethnographic synthesis capture the experiences of 378 parents (279 mothers and 99 fathers). The studies were conducted across 12 countries (Australia, Canada, China, Greece, Ireland, Scotland, Spain, Sweden, Thailand, Turkey, UK, USA). In 13 of the studies, the parents were caring for adult children, in 11 studies the children were under 18 years of age, and in one study the ages of the children were not specified. In several studies, it was unclear from the recruitment and sampling strategies whether the children were currently receiving treatment, and if so, whether this was in an inpatient or community setting. A small number of studies specified that the children were living at home and/or receiving community treatment, while three studies specified that participants were recruited via both inpatient and community settings. One study stated that the children were in a "day hospital" and another study stated the children were receiving "intensive specialist treatment"; it was not clear what these terms meant.

The synthesis is expressed below, with each of the key concepts first explored in detail; the line of argument synthesis is subsequently described and expressed through a model depicting the psychological processes experienced by parents.

Caring for an Intimate Stranger

Transformation of the Loved Child. This phrase came from a theme in Tuck's (1997) study involving parents of adult children with schizophrenia in the USA, but the concept featured in almost every study. As the child became ill, parents witnessed a "malevolent transformation of a loved one who remains physically present in their world" (Tuck, 1997), reminiscent of Boss' (2002) concept of ambiguous loss. The significant changes that parents noticed in their child required them to parent their child differently. This was described as "parenting in overdrive" in a study involving parents of adolescent children with depression in the UK (Stapley et al., 2016), as the child, rather than developing independence, became more dependent with age. The extent of this change was captured in a study of parents of adolescent children with eating disorders in Sweden, in which parents had to behave as though caring for a toddler, rather than their late-teenage child (Svensson et al., 2013).

The studies captured how parents perceived their child to be significantly different as a consequence of their illness, rendering the child almost unrecognisable at times. This featured in studies involving parents of adult children as well as young children. In one study of Thai mothers caring for an adult child with schizophrenia, mothers thought their child looked “like a stranger” or as though they were possessed (Kanungpiarn, 2021). This experience of simultaneously recognising and not recognising was captured by Darmi et al. (2017), who described how Greek parents of adult children with psychosis were “caring for an intimate stranger”.

Parents of adult children with psychosis had some differing experiences. For many, there was a sense that the changes within their child were so profound that there was “no going back” (Mohr & Regan-Kubinski, 2001) and no way to restore the “pre-illness normal state” of their child (Poonnotok et al., 2016). Some parents, however, perceived there to be “a core part” of the child that was unchanged (Tuck, 1997), enabling them to “glimpse” the pre-illness child at times (Pejlert, 2001; Tuck, 1997), engendering hope.

Despite this, most studies described feelings of loss over the transformation of the child. One study of UK mothers’ experiences of having an adolescent child with depression conveyed this with the theme “depression causes change” (Armitage et al., 2020), which encompassed the loss of connection with the child, the loss of the child’s personality, and the loss of normal family life. In some studies, the profound effect of the transformation of the child caused parents to feel as though the child were not only changed but gone entirely. Parents of adolescent children with various mental illnesses in Spain wanted to “get back” their lost child (Sarrio-Colasa et al., 2022), and the loss of the “ideal child” was mourned by the parents of adolescent children with Tourette’s Syndrome in Australia (O’Hare, 2017). The sense of loss experienced by Swedish parents of adult children with various mental illnesses created feelings of grief and “constant sorrow” (Johansson, 2010).

A Psychological Tsunami of Emotions. McAuliffe (2014) used the metaphor of a “psychological tsunami” to describe the devastation experienced by parents. Parents experienced emotions including (but not limited to) shock, fear, grief, guilt, anger, and helplessness which began at the time of noticing changes in their child and were often compounded at the point of diagnosis. The painful emotions were unrelenting during the course of the child’s illness, meaning that parents were described as “living worried” (O’Hare, 2017), experiencing “suffering as a way of life” (Donnelly, 2001), and learning to “live with a constant sadness” (Johansson, 2012). When considered together with the grief and mourning described in the previous paragraph, this is suggestive of Olshansky’s (1962) concept of chronic sorrow.

Many parents worried about their own culpability in their child’s illness, causing them to question their ability as parents. Scottish parents of adolescent children with various mental illnesses felt shame and regret and were tormented by guilt, particularly in the beginning of their child's illness (Harden, 2005b), believing themselves to be "failing as parents" (Harden, 2005a). Feelings of uncertainty and powerlessness created a "disconcerting emptiness" (Mohr & Regan-Kubinski, 2001), and experiences of stigma and judgement exacerbated parents' struggles. This was described as "distressing loneliness" in a study involving parents of pre-adolescent children with bipolar affective disorder in the USA (Wade, 2006). For some parents, matters were further complicated by a belief that they had to conceal their emotions (Armitage et al., 2020) or attempt to uphold positive feelings (Kanungpiarn, 2021) in order to help their child. The complexity and intensity of emotional experiences was apparent across the studies, with the array of difficult emotions described as "turmoil" in studies conducted both in the UK (Stapley et al., 2016) and the USA (Raymond et al., 2017).

Emotional turmoil was evidently a prominent aspect of parents' experiences, such that the central themes in one study of Swedish mothers' experiences were "mourning, loss, and the sense of a never-ending burden" (Piuva & Brodin, 2020). The concept "a psychological tsunami of emotions" featured in all but two of the studies; in the two studies in which this concept was not present, the results sections were brief and did not provide detail on the emotional experiences of the parents, who were caring for adolescent children with various mental illnesses in Spain (Sarrio-Colasa et al., 2022) and adolescent children with anorexia in the UK (Thomson et al., 2014).

Turning Point

Realisation. In the majority of studies, the authors described moments when parents came to a realisation regarding their child's difficulties. For most, this was either at the time of recognising the child's symptoms, after an acute episode of psychological distress, or at the time of diagnosis. In any case, parents were forced to acknowledge the extent of their child's difficulties.

These important moments of realisation for families were crucial in the narration of events, with time seemingly "sharply divided" (Tuck, 1997) into life before and life after the onset of illness or the diagnosis in many studies. Experiences of diagnosis varied. Receiving a diagnosis of bipolar disorder for a pre-adolescent child caused relief (Wade, 2006) when it had been preceded by previous misdiagnoses, incorrect medication, and a strong sense that something was wrong. Similarly, diagnosis provided a decrease in anxiety for mothers of adult children with various mental illnesses in Sweden because it facilitated an improved understanding of the child's difficulties (Johansson, 2010). However, the majority of studies described intense, often negative, emotions connected to receiving a diagnosis; a diagnosis of Tourette's Syndrome was experienced as a "highly traumatic major life event" by Australian parents of young children (O'Hare, 2017). Furthermore, a diagnosis of schizophrenia, in particular, appeared to be received negatively and incited significant concern in the parents. Parents in China experienced this diagnosis as overwhelming and hard to accept (Bai et al., 2020), and Canadian parents experienced "devastation" as a result of the diagnosis (Wiens & Daniluk, 2009). Parents in Thailand perceived a diagnosis of schizophrenia to mean "facing shattered dreams" (Poonnotok et al., 2016).

In other studies, a moment of realisation came only after traditional healing methods had been tried and failed. In a study involving Korean American parents of adult children, the moment of realisation was a point of crisis reached when "traditional" or "folk" healing methods had been ineffective, giving them no option other than to pursue so-called "Western" treatments (such as medication); this was conceptualised by the sub-theme "awakening" (Donnelly, 2001). Similarly, for Thai mothers caring for adult children, an important turning point occurred after they had tried combining traditional and Western treatments, as it followed that they discovered that modern medicine could help their child (Kanungpiarn, 2021).

The time it took for parents to come to a point of realisation varied both within and across studies. This was captured by Mohr and Regan-Kubinski (2001) who noted that this "ranged from a gradual perception to a sudden realisation".

Getting Help. Every study described parents' experiences of seeking and/or receiving help for their child. The help-seeking process was often complicated, with parents not knowing how or where to obtain support (Johansson, 2010; Armitage et al., 2020). Nevertheless, parents searched for answers and for help, desperate to know how to support their child (Tuck, 1997; Poonnotok et al., 2016).

When they did access support, many were frustrated or disappointed with the help they received (Pejlert, 2001; Mohr & Regan-Kubinski, 2001; Harden, 2005a; Harden, 2005b; Wade, 2006; Wiens & Daniluk, 2009; Johansson, 2012; McAuliffe, 2014; McCormack & McCann, 2015; Stapley et al., 2016; Raymond et al., 2017; Piuva & Brodin, 2020; Armitage et al., 2020; Gok & Duyan, 2020; Sarrio-Colasa et al., 2022). Some particular factors contributed to parents' dissatisfaction. In a study that focused specifically on fathers' experiences of caring for adult children with various mental illnesses, fathers felt ignored, and perceived healthcare professionals as taking little interest in their caregiving role (Johansson, 2012). Other parents felt excluded from care (Harden, 2005a, in Scotland) or treated insensitively by professionals (Gok & Duyan, 2020, in Turkey). Positive experiences of healthcare were described in only a few studies (Svensson et al., 2013; McCormack & McCann, 2015; Piuva & Brodin, 2020). It was not possible to identify whether there were particular characteristics of the samples in these three studies that would explain why these participants reported positive experiences while participants in other studies did not. For example, these were not the only studies in the review to have been conducted in these countries (Ireland and Sweden), the ages of the children (adults and adolescents) were non-specific, and the diagnoses (eating disorders and unspecified "serious mental illnesses") also featured in other studies.

For families, the process of getting help was generally long and convoluted, described by authors as a "long journey" (Raymond et al., 2017) or a "long road" (Sarrio-Colasa et al., 2022). Even when help was given, this brought up complicated feelings for parents. Parents of adult children with schizophrenia who were living in residential care in Sweden experienced guilt and shame, which they connected to critical comments from professionals and an uncomfortable atmosphere on the ward (Pejlert, 2001). It was noted that the parents in this study favoured a psychosocial understanding of their child's distress as opposed to the medical model, but that this perhaps contributed to feelings of guilt and shame when parents wondered how their own parenting had contributed to their child's difficulties. In another study involving parents of adult children with schizophrenia or a major affective disorder in the USA, parents found that the process of getting help for their child did not provide closure, and that treatment instead reinforced their worries that their child's illness could get worse (Mohr & Regan-Kubinski, 2001). These parents also believed that their children experienced involuntary inpatient treatment as a "breach of trust" by the parents. Parents of adult children with psychotic disorders in Greece had changing perceptions of treatment over time, but similarly experienced professionals as judgemental, and doubted the ability of professionals to help their child (Darmi et al., 2017). In this study, treatment was understood to be medication and hospitalisation; psychological treatments were not discussed. Parents viewed medication as essential but had concerns about the side-effects, leaving them with a sense that treatment was "cruel but necessary".

Unavoidable Role

Gendered Caregiving. This concept, although it featured in fewer than half of the studies, captured some of the important differences in caregiving between mothers and fathers, and therefore was important to include in this review of parental experiences. This concept generally captured how mothers assumed the main caregiving role, but in two studies, the importance of spousal support was also mentioned (Svensson et al., 2013; Gok & Duyan, 2020). However, none of the studies suggested that fathers adopted the main caregiving responsibilities; even in a study which had a sample consisting only of fathers, fathers still "described the mother as carrying the heaviest burden" (Johansson, 2012). It is not possible to say whether the lack of discussion around gender roles in many of the studies was because it was not described by parents in those interviews, or because the authors did not focus on this area in their analysis and write-up of the results.

Commitment. Parents differed slightly in how they appraised the experience of caring for their child. Two studies remarked on how none of the parents used the word "burden" to describe their experiences (Wade, 2006; McAuliffe, 2014), while other authors chose to use this word to describe parental experiences, such as "a huge burden" (Darmi et al., 2017) and "a never-ending burden" (Piuva & Brodin, 2020). However, irrespective of choice of language, it was evident that parents in the studies were committed to their caregiving role regardless of the self-sacrifice it required. The language used to describe the caregiving role conveyed how this was a role that the parents could not avoid: they were "trapped" (Darmi et al., 2017) and "forced" (O'Hare, 2017), had "responsibility" (Wiens & Daniluk, 2009), "no choice" (Wade, 2006), "no escape" (Mohr & Regan-Kubinski, 2001), and, moreover, "no hope of escaping" (Donnelly, 2001). Parents perceived their role as unavoidable both when considering it in the present and when imagining the future ("no matter what happened, they had to stay together with their ill children and take care of each other for the rest of their lives" (Kanungpiarn, 2021)) and language chosen by authors again conveyed a sense of obligation: parents never considered "abdicating" their caregiving role (McAuliffe, 2014). "Caregiving as an unavoidable role" (Poonnotok et al., 2016) captured the experiences of parents overall.

An Impossible Task. Caring for a child with a mental illness was described as an immense task. The nature of the caregiving role was such that it was impossible for parents to get it right all of the time. This led to feelings of despair, such as when fathers realised that their determination to help their child was not enough (Johansson, 2012), or when parents of children with eating disorders found that irrespective of how much they tried to help their child, the child would not recover (Svensson et al., 2013). Furthermore, when faced with the difficulty of their task, parents were also painfully aware of what was at stake: the "potentially disastrous effect of a weak moment" (Armitage et al., 2020). The result was profound feelings of helplessness, powerlessness, and uncertainty, emotively described in one study as "living a life under constant strain" (Johansson, 2010).

Uncertain Future

Uncertain Future. The future was viewed by parents in complex ways. They experienced anxiety and fear as well as hopefulness when thinking about the future of their child and of the implications this would have on their own futures. It seemed important for parents to maintain hope and to "see light in the darkness" (Johansson, 2010) as it enabled them to carry on (Tuck, 1997). However, maintaining hopefulness or optimism was difficult to do (O'Hare, 2017) and some parents struggled to even talk about the future (Sarrio-Colasa et al., 2022). Others thought it was important to be realistic about the future (Raymond et al., 2017), and perhaps some parents did not want to engage in hopeful feelings, given that hope was considered "inseparable from the risk of disappointment" (Tuck, 1997).

When juxtaposed, the existence of these seemingly conflictual emotions was illustrative of the uncertainty of the futures faced by the families.

Transcendence

Reframing Thinking. In many of the studies, parents adjusted their expectations and reframed the way they thought about their child and the future. Parents were not always aware of this process; it seemed at times to be a conscious coping strategy which helped them to accept their situation, enabling them to continue caring for their child, and at other times, a by-product of other strategies they were using.

Religious and spiritual practices were examples of one way in which parents were able to think differently about their experiences as a consequence of using an existing coping strategy. Prayer was used by Korean American parents and allowed them to "shift their view of suffering" (Donnelly, 2001) and religious beliefs brought Thai parents feelings of peace (Kanungpiarn, 2021). Unlike other studies in this review, in Kanungpiarn's (2021) study the Thai mothers believed that their present suffering was caused by wrongdoings in a past life; this religious and cultural understanding of their current difficulties was comforting for them.

The authors suggested that mental health services in Thailand should promote religious practices as a way of helping parents positively reframe events.

Studies also reported on the conscious efforts parents made to adjust the expectations they held about their child and the future (Poonnotok et al., 2016; Raymond et al., 2017; Kanungpiarn, 2021), recognising that their child may not lead a normal life, re-evaluating goals, and lowering expectations. Parents made conscious efforts to focus on positives, such as the good things in life (Pejlert, 2001), the love they felt for their child (McAuliffe, 2014), their child's strength (Wiens & Daniluk, 2009), the positive aspects of their child's illness and of their experience as parents (McCormack & McCann, 2015), and by noticing that the "positives outweigh the negatives" (Wade, 2006).

The process of accepting the child's illness, adjusting expectations, and focusing on the positives afforded parents different perspectives on their lives and their futures. These conscious efforts to reframe their thinking, as well as religious practices and beliefs, were some of the ways in which parents were able to transcend their suffering.

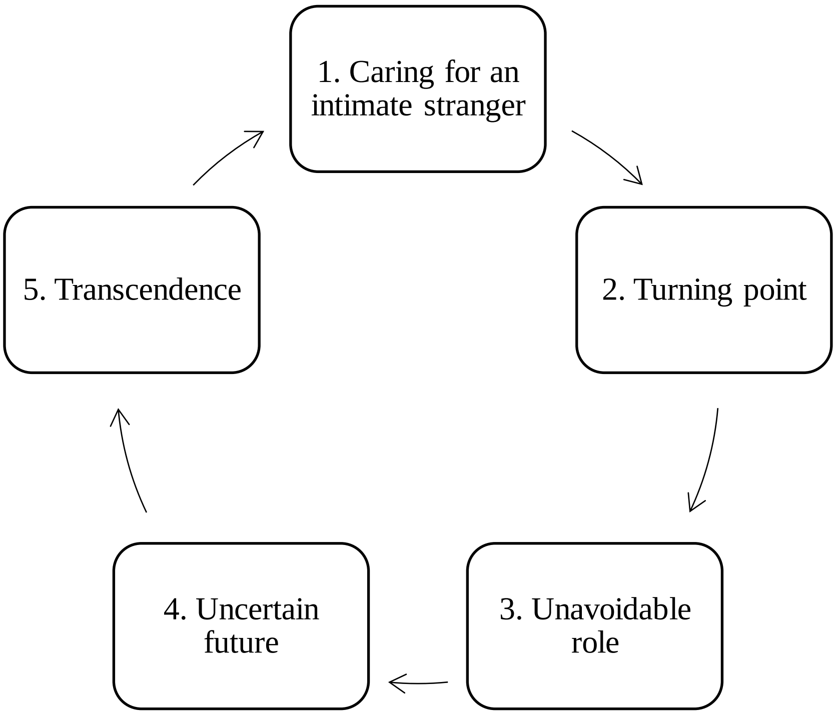
Finding Meaning. Parents felt that they had no option other than to continue caring for their child, despite their suffering. Finding meaning in their suffering and in their experiences afforded them the strength to continue, moving away from "ordinary caregiving experiences" (Donnelly, 2001). Parents felt that they had found a purpose in life (McAuliffe, 2014), learned about themselves (Wiens & Daniluk, 2009), or learned to identify what the real issues were in life (Piuva & Brodin, 2020). Others found meaning directly through their child, who they felt had made it "all worthwhile" (Wade, 2006). However, this concept did not feature in all of the studies, suggesting that not all parents had found meaning in their experiences. Parents across the studies were caring for children who were at different stages of diagnosis, treatment, and recovery; this may partly explain why only a small number of studies described experiences of finding meaning.

Line of Argument Synthesis

All key concepts derived from the studies were illustrative of processes experienced by parents who care for a child with a mental illness. This suggested that it would be possible to bring together these concepts and reciprocal translations in order to create a line of argument synthesis (Noblit & Hare, 1988) which goes beyond explaining the key concepts within the studies in order to develop a grounded theory (Noblit & Hare, 1988, as cited in Toye et al., 2014). In this way, the whole is greater than the sum of its parts (Noblit & Hare, 1988). The line of argument synthesis which follows depicts the temporal, subjective, psychological experiences of parents. A diagram was developed to present this line of argument (Figure 4).

Figure 4

The Psychological Processes Experienced by Parents of Children with Mental Illnesses



This model proposes a cyclical process through which parents pass when caring for a child with a mental illness. This model is characterised by five stages, each depicting a transitional point in which parents re-evaluate their experiences. Similar to Karp's (1994) five-stage portrayal of the "ongoing identity shifts" of people experiencing depression, these stages involve a reassessment of one's identity and of one's life as a parent of a child with a mental illness.

The five-stage psychological process begins with parents noticing changes in their child. This first stage is characterised by painful emotions and shock and leads parents to feel as though they are caring for a stranger, as their child is experienced as unrecognisable. Consequently, parents search for answers; the second stage is experienced as a turning point, marked by the realisation that their child has a mental illness, and by starting to seek and receive help for their child. However, this perceived turning point does not manifest in the way that parents had anticipated. As parents engage with the healthcare system and learn more about their child's illness, they lose some of the hope that they had held previously.

This leads to the third stage, in which parents instead face the unavoidable role of caring for their child. This role is experienced, at times, as impossibly difficult. The fourth stage is characterised by uncertainty: the future of both the child and the family feels unknown, and tentative moments of hope are offset by anxiety and fear. Parents, however, feel that they have no choice other than to continue caring for their child, whom they love. They find a way to cope; this final, fifth stage depicts how parents attempt to reframe their thinking and find meaning in their experiences in order to transcend their suffering.

The model is cyclical, rather than linear, because recovery from a mental illness is not a linear process, and, as such, caregiving is not experienced as linear. Children may experience periods of recovery followed by relapses, and they may go through changes in psychological or pharmacological treatments or move between outpatient and inpatient care, all of which may affect the caregiving experience. In this review, while some of the parents had young children, others had been caring for a (now adult) child with an enduring mental illness for decades; the model would therefore suggest that parents may pass through this cycle many times over the course of caring for a child with a mental illness. For instance, parents may reach the fifth, final stage of the cycle and remain here for some time, before a relapse or some deterioration in the child’s mental health means that they are faced again with a transformation in their child – stage one of the cycle.

However, parents’ experiences are temporally structured, evolving over time. Parents who return to the first stage of the cycle will have learned from their prior experiences, likely having committed to their caregiving role and found meaning in their experiences so far. The ability to draw on previous experiences may mean that parents now pass through the stages more quickly. They may also experience the stages differently when revisiting them, engaging with each stage in a new way, and able to approach them with increased understanding and insight which will lead to further development. As such, not all parents will experience all stages of the cycle in the same way. They will pass through these stages at different speeds, and some parents will spend more time in one stage than another. Specific sets of circumstances may mean that some parents remain at earlier stages of the cycle, while others reach the final stage and remain there. The cyclical component of the model is important but should not be taken to imply that all parents will pass through all stages, or that all parents will cycle through them in the same way.

Thus, this model of the psychological processes of parents of children with mental illnesses proposes that parents cycle through five stages, encompassing the period from witnessing initial changes in their child to finding a way to transcend their suffering. Parents look for a way to transform their pain to a lesser or greater degree in order to be able to continue caring for their child. Furthermore, the ability to draw on past experiences, to reframe their thinking, and to find meaning in their experiences will serve to move them more quickly through the cycle if there are times in their lives when they return to earlier stages of the cycle.

Discussion

This qualitative review has provided a meta-ethnographic synthesis of 25 qualitative studies of parents' experiences of caring for a child with a mental illness. The line of argument synthesis illustrates a cyclical, five-stage process through which parents may pass: caring for an intimate stranger, turning point, unavoidable role, uncertain future, and transcendence. While not all parents will pass through the cycle in the same way, the proposed model offers a new way of understanding parental experiences within this context and highlights the complex psychological processes that parents endure.

Just as other models and theories have been extrapolated to different populations (chronic sorrow (Olshansky, 1962) has been applied to mental illness (Eakes, 1995), and ambiguous loss (Boss, 2002) has been applied to brain injury (Flores, 2021) among other conditions), the model proposed in this meta-ethnographic synthesis may have wider implications. It is possible that the model of the psychological processes of parents caring for children with mental illnesses may be applicable to parents of children with other difficulties, such as emerging disabilities or physical health problems. Future research could attempt to determine whether this is the case.

A methodological issue with existing research on the topic, as highlighted by this review, is that many researchers have failed to make clear the inclusion and exclusion criteria relating to the participants' child. The consequence of this is that it is not possible to determine whether children were receiving treatment at the time of the parents' interviews, and more importantly, the context of treatment is unknown. Therefore, it is likely, in many of the studies included in this review, that parental experiences were amalgamated despite vastly different circumstances; parents of children who receive community treatment will have different experiences to those of children who receive inpatient treatment. The context of the child's treatment at the time of the parent's interview is likely to impact how a parent makes sense of his/her experiences.

In the studies included in this review, some researchers chose to focus on parents of young children (under 18 years old) while others studied the experiences of parenting adult children (aged 18 and over). Generally, researchers did not provide a clear rationale for their choice of age group. It was also remarkable that in many of the studies concerning adult children, the ages varied widely. For example, in a study of mothers' experiences (Johansson, 2010), the children's ages ranged between 18 and 49 years. It would be problematic to assume that parents of an 18-year-old have comparable experiences to parents of a 49-year-old, and yet, in many of the studies, differences in age and life-stage were not discussed.

Research Question and Aim

It is necessary to further investigate parental experiences of having a child with a mental illness, with the aforementioned methodological and sampling issues addressed. Of the three studies conducted in the UK (Thomson et al., 2014; Stapley et al., 2016; Armitage et al., 2020), none investigated parental experiences in the context of inpatient treatment. While studies outside of the UK have recruited partly via inpatient settings (Poonnotok et al., 2016; Darmi et al., 2017; Raymond et al., 2017), these studies also included parents of children receiving treatment in the community and parents of adult children; it was not possible to distinguish between the groups in the results. Therefore, to date, no research has investigated the experiences of parents of children who are specifically receiving inpatient treatment and are under 18 years old. As such, the aim of this research is to explore the subjective experiences of parents of children who are receiving treatment in inpatient child and adolescent mental health services in the UK.

Methods

This chapter provides an account of the methods used in this research. Various theoretical and philosophical ideologies that can inform theories about reality (ontology) and about how this reality can be known (epistemology) are described, and the rationale is given for framing the research with a critical realist ontology and conducting it within a contextualist epistemology. An overview of qualitative and quantitative methodologies is then provided, and the rationale for using a qualitative methodology is given. Narrative Analysis is chosen as the most appropriate analytical method and is discussed in relation to other qualitative approaches to data analysis. Finally, the procedures (participant recruitment, data collection and data analysis) and ethical considerations are described in detail.

Ontology

The ways in which research is designed, data is collected and analysed, and conclusions are drawn are all shaped by a researcher's view of whether, and the extent to which, research can represent reality. Therefore, for the purposes of this study, it is important to situate the research within the ontological position held by the researcher. A critical realist ontology framed the research, and this is described below. However, in order to demonstrate the appropriateness of this ontological position for the present study, two contrasting ontologies are also discussed: realism and relativism.

Realism

A researcher subscribing to this ontological position would deem the data they collect to be representative of the reality of that which they are studying. This position lends itself well to some of the natural sciences where one might maintain that the world is as it appears to be, and that the representation of reality within the data is the same as reality itself (Braun & Clarke, 2022, p.168). The aim of research, therefore, is to access some "truth" about the world (Fletcher, 1996), and this truth or reality is understood to be there already, whether we decide to study it or not (Burr, 1998, p.18).

Relativism

In stark contrast to realism, researchers taking a relativist stance are less concerned in generating data and forming conclusions that depict a "truth" about the world, instead, they reject the notion of there being a singular reality (Braun & Clarke, 2022, p.173). Relativists argue that there is no such thing as a ready-made "real world"; instead, there are many versions of the same world (Goodman, 1996). Any phenomenon exists only relative to an observer, a theory, or an ideology, for example (Nola, 1988, p.10), and therefore data collected in research portrays just one version of reality.

Braun and Clarke (2022, pp.173-174) note that relativist ontology considers reality to be the consequence of "action and interaction", and it is helpful for some types of qualitative research, such as when analysis is focused on the meaning-making processes in which participants engage.

Critical Realism

This position is one which holds the previous two ontologies "in tension" with each other (Ferguson, 2022). Critical realism allows researchers to accept that there is value in the scientific method while remaining cognisant that there are several types of reality; this has been described as a "resolution" or "merging" of realism and relativism (Bergin et al., 2008).

Any knowledge that can be acquired is considered to be influenced by culture, language, theory, and so on, and thus acquiring knowledge is a social process which is relative to the people, systems and structures involved (Ferguson, 2022). This differs from a relativist position in that the notion of a reality is somewhat accepted, insofar as it determines or restrains what is possible to uncover (Braun & Clarke, 2022, p.170). Cramer and Howitt (2020) write that "language […] is not reality but just a window on reality", again illustrating that there is a reality, but one that is accessible only through the language, meanings, and interpretations of humans, rendering it constructed in some way by participant, researcher, society, and so on. This is a comfortable position from which to approach the present research, acknowledging that when speaking to a person about their experiences, language is used to convey their reality, but this reality is also constructed in the process of using language. How a person experiences events and circumstances is therefore shaped by their individual history, their culture, their context, and the stories they entertain about the world.

Epistemology

Epistemologies represent philosophies about the types of knowledge that are deemed useful or valid and dictate how that knowledge can be accessed through research (Braun & Clarke, 2022, p.175). Four epistemologies commonly used in qualitative research, and related to the ontologies already described, were considered: positivism, post-positivism, constructionism, and contextualism. A contextualist position was held in this research, but these four epistemologies are discussed below, in order to make explicit how a contextualist epistemological position most suitably underpins the research.

Positivism and Post-Positivism

From a truly positivist position, the knowledge derived from research is considered objective and factual, as there is a "direct relationship" between what is being studied/observed and how it is represented in the research (Willig, 2001, p.3). Positivism therefore draws on empiricism, sharing the view that "scientific knowledge should in some way be derived from the facts arrived at by observation" (Chalmers, 1999). Often paired with a realist ontology, a positivist researcher is concerned with collecting data that reveals an existing reality, and value is placed on objectivity and generalisability.

However, the fallibility of so-called "observable facts" (Chalmers, 1999, p.25) is now well-documented, and it is argued that researchers today are unlikely to position themselves as truly positivist (Willig, 2001; Braun & Clarke, 2022, p.177). Instead, a post-positivist framework now underpins most scientific research including within the social sciences

(Braun & Clarke, 2022, pp.177-8), whereby although the aim remains to collect objective data, researchers acknowledge that data is rarely free from the influence of the researcher's existing pre-conceptions, values, and ideas. Thus, while the degree to which researchers accept or reject notions of "truth" varies (Willig, 2001, p.3), a post-positivist stance nonetheless acknowledges that the data collected through observations and experiments do not necessarily portray an objective and unbiased view of the phenomena being studied.

Constructionism

In contrast to a positivist epistemology, constructionists view reality as produced, rather than revealed, by research (Willig, 1999). There is a strong focus on language as central to the research process (Braun & Clarke, 2022, p.180). Language is understood to create reality rather than simply being a conduit for communicating reality – an idea that constructionists "profoundly distrust" (Madill et al., 2000). Constructionists often hold a relativist ontology and argue that there is no foundation for reality, as reality is constructed by human practices (Braun & Clarke, 2022, p.183).

Contextualism

Within a contextualist epistemology, researchers accept that knowledge is partial, provisional, and permeable (Madill et al., 2000; Braun & Clarke, 2022, p.178; Stiles, 1993). The researcher and the researched are involved in a co-production of knowledge and meaning. This co-production of data is influenced by how participants understand their experience, by how the researcher interprets this, by the cultural systems (context) which inform how participant and researcher make these interpretations, and, finally, by how membership of a scientific community affects how one judges the validity of any interpretation (Pidgeon & Henwood, 1997). Given these many influences, researchers approaching research from this epistemological position are likely to reject philosophies of objectivity and reliability as they do not subscribe to the belief that methodology can yield data which captures a pre-existing reality (Madill et al., 2000). This epistemology is therefore well-aligned, and often paired, with a critical realist ontology.

Although importance is not placed on objectivity within a contextualist epistemology, this is not to say that researchers remain ignorant of their own influence on the data. Instead, it is considered important for researchers to actively consider and to articulate the perspective from which they approach their data (Madill et al., 2000). The researcher would accept that it is impossible to detach oneself from one's context when co-constructing and analysing data; it therefore becomes important to name, and to reflect, on the aspects of one's own background that may shape how they approach their data, and whether these are shared, or in contrast, with that of the participants.

Pidgeon & Henwood (1997, p.251) wrote that a researcher must also attempt to seek the participants' "tacit" in order to see things from their perspective and to understand their position in their world. One needs also to consider how the participants' own contexts, cultures, and circumstances provide them with a "frame of reference" to understand their own world. This is described as the "insider perspective". Contrastingly, the researcher simultaneously attempts to maintain some distance from his/her participants (Pidgeon & Henwood, 1997, p.251), and there is therefore an attempt to seek both insider and outsider perspectives. The authors wrote that maintaining distance or "strangeness" dissuades the researcher from accepting data at face value. However, the authors note that this is not to be conflated with a realist, positivist stance in which objectivity is paramount, as a researcher working within a contextualist paradigm is not neutral or passive in the production or analysis of data. Knowledge is contextually situated and grounded, co-constructed by researcher and participant, and data analysis is partial and perspectival but can nonetheless shed light on the underlying social practices of participants (Braun & Clarke, 2022, pp.178-179; Madill et al., 2000). This perspective was maintained during the present research.

Researcher Position Statement

I approach this topic with professional experience in the area. My interest in the topic, and my reason for undertaking the research, stems from working in an inpatient CAMHS ward between 2017-2019. I was employed as a Healthcare Assistant on a twelve-bedded ward for children aged 12-17 who had diagnoses of mental illnesses. This was a uniquely challenging role, and one that, I believe, continues to shape the practitioner I am today.

I have clear memories from this time of observing parents who visited their children on the ward. I can remember speaking to parents who were highly distressed – worried, sad, angry, exhausted – and being acutely aware that my colleagues and I did not have the time or resources needed in order to support these parents. This was irrespective of how much we wanted to listen and talk to these parents, and how much we believed they were deserving of help. I remember parents leaving the ward in tears after visiting their child, and finding myself wondering how they would cope when their child was discharged from the ward.

I believe that clinicians working in inpatient CAMHS wards are often doing their best to work compassionately under challenging circumstances. Having experienced the internal conflict that emerges when one wants to help parents but lacks the resources to do so, I am interested in conducting research that will allow me to speak to parents like those I met during my time working on an inpatient CAMHS ward. I hope that this research will bring attention to the experiences of parents of children in inpatient CAMHS and help professionals to better understand them and their difficulties. My hope for the future is that this research will encourage others (researchers and clinicians) to consider how to increase the support provided to parents, so that professionals have the necessary resources available to support parents, parental wellbeing and quality of life improve, and parents therefore feel well-equipped to support their children.

Research Methodology and Design

Quantitative and Qualitative Methods

Following the emergence of positivism in the 19th century and the rise of positivist social science during the 20th century, quantitative methods were positioned as superior and more "scientific" than methods of qualitative inquiry (Leavy, 2014, p.17). The quantification of psychological research, facilitated by drawing on positivist approaches from other disciplines including physics and medicine, was the driving force that led to the development of psychology into major research and clinical fields (Cramer & Howitt., 2020, p.364).

Quantitative methods allow for a degree of precision in measurement and comparison of different phenomena (Barker et al., 2002, p.54). These methods, however, can neglect some of the nuances and idiosyncrasies that exist in data, meaning the richness of phenomena is not necessarily captured. The instruments of measurement used can be experienced as crude and alienating by participants, perhaps leaving them feeling that the research does not adequately capture their experiences; some view the human experience to be too complex to be reduced to the variables adopted in quantitative methods (Cramer & Howitt, 2020, p.366). In qualitative research, data is typically gathered in a less structured or systematic manner; qualitative researchers are less likely to comment on generalisability and are more likely to adopt a post-positivist position (Cramer & Howitt, 2020, p.375). The resulting datasets, often interview transcripts, provide rich and in-depth information on the topic being studied, informing an understanding of subjective human experiences.

Qualitative Analysis

It has been argued that the illness experience has an "expressive quality" that is lost when researchers attempt to quantify it, and illness must therefore be studied qualitatively if researchers are to understand how people make sense of their illness experiences (Murray, 1999, p.22). Different qualitative methods were considered for this research, and Narrative Analysis was chosen as the most appropriate method. The rationale for this choice is described below.

There has been an increased interest in narrative methods within the social sciences over the last three decades (e.g. Polkinghorne, 1988), perhaps in part because we all live in a “storied world”, interpreting our experiences and defining ourselves through stories (Murray, 1999). Narratives are the stories that we tell about our lives, and narrative approaches emphasise preserving the contexts in which participants tell these stories (Gray et al., 2005). Narrative analysis allows both the narrator and audience to understand an experience and is considered an "especially powerful" methodology when the narratives being studied are accounts of crises or significant incidents in people's lives or relationships (Cortazzi, 2001), as was the case in this research. Importantly, narrative theory is considered useful for understanding subjective human experiences in general, but experiences of illness in particular (Ezzy, 2000).

Some qualitative approaches to data analysis still fragment the experiences of participants, abstracting words from their context (Murray, 1999; Gray et al., 2005). Thematic analysis, for instance, focuses on identifying patterns of meaning across a dataset (Braun & Clarke, 2012). The data are coded systematically in order to identify themes which attempt to capture the experiences of participants (Braun & Clarke, 2006). By way of the coding process, discourse is fragmented and reduced to small units of analysis, in contrast to narrative approaches which make use of “longer stretches of talk” that are not broken apart by the researcher (Murray, 1999). A narrative approach to the study of experiences of illness is thought to allow for a more intimate and complex understanding than traditional health psychology (Gray et al., 2005) – a level of understanding that may otherwise be lost during the process of reducing discourse into discrete units (codes). Polkinghorne’s (1988, p.11) core argument was that narratives are used by humans to give meaning to their experiences; given that the experiences of parents of children in inpatient CAMHS had never been explored before, it was important that these participants’ narratives were not fragmented to allow for a detailed analysis of their experiences.

The analytical method needed to be congruent with the philosophical positioning of the research. The assumptions about knowledge and how knowledge can be acquired that were underpinning the research meant that the analytical method would need to acknowledge that participants' realities are socially constructed and that their stories are co-produced within the research setting (Barker et al., 2002, p.12). With this in mind, one of the advantages of narrative analysis is that it acknowledges interpersonal influences on the construction of narratives. Murray (1999, p.55) commented on the debate amongst psychological researchers regarding the "frequent ignorance" of this interpersonal context, highlighting that within narrative theory it is instead acknowledged that narrators will tell different stories to different audiences. Given the subject matter, and the likelihood that participants would be describing difficult and emotive experiences, it was also necessary to consider whether there were sociocultural contexts enabling or disabling participants from sharing information in interviews. A narrative approach would facilitate this in the analytical process, given its emphasis on preserving the contexts in which participants tell their stories in order to reveal social structures and processes (Gray et al., 2005).

Participants

The recruitment strategies described here were chosen in order to generate a sample of participants with experiences directly related to the research questions.

Sample Size. Sample size was considered first in relation to the dearth of existing literature on the topic. While sample sizes in qualitative research tend to be smaller than in quantitative research (Barker et al., 2002, p.185), with some methods such as Interpretative Phenomenological Analysis (IPA) calling for fewer than ten participants (Creswell & Poth, 2007, p.131) or even single-case studies (Smith & Osborn, 2008), such a small sample would have made it difficult to sufficiently explore parental experiences in this study. Furthermore, homogeneity of sampling was not needed in the way that is required for IPA, and it was more important to capture a range of experiences within the target group. The target group, however, was small, given that there are only a "very small" number of inpatient CAMHS beds – approximately 1,600 beds for adolescents across the whole of England, according to the Association for Young People's Health (AYPH, 2021).

In a review of sample sizes in qualitative research, Marshall et al. (2013) suggested that one of the best practices for justifying sample size is to cite existing studies that have used similar designs to answer similar research questions. The authors noted that researchers should then use this information to allow them to "act on the precedent" of other, similar, studies.

Samples sizes in related literature have varied somewhat. The meta-ethnographic synthesis, which was conducted prior to the present study, included studies with samples ranging from six (McAuliffe, 2014; Wiens & Daniluk, 2009) to 48 (Stapley, Midgley & Target 2016) participants. The mean average number of participants was 15.75. Given the contact time that will be spent with each participant to conduct in-depth interviews, and the time that will be devoted to carrying out narrative analysis of the interviews, it was justifiable to take these factors into consideration when determining the desired sample size (Marshall et al., 2013).

Other pragmatic considerations also informed the decision about sample size. An awareness of the total number of children on each of the wards at any one time, with long admissions meaning less turnover of patients, influenced estimates of the total number of participants that could feasibly be recruited. Furthermore, of the services that were identified for this research, the majority were not operating at full bed capacity, meaning that there were significantly fewer patients, and therefore fewer parents, from which to sample. Some services were filling fewer than half of their available beds at the point of recruitment due to ward-specific restrictions or difficulties. A final, important, consideration was around what would be deemed acceptable by the services and the staff members supporting recruitment, given that services are under pressure and staff members are busy. With this in mind, the aim was to recruit between twelve to sixteen participants in total. This is also consistent with the mean number of participants in the related studies reviewed in the meta-ethnographic synthesis, as highlighted above.

Inclusion and Exclusion Criteria. The inclusion criteria were as follows: (a) a mother, father, or primary caregiver (described in this thesis as “parents” for readability), (b) of a child who is receiving treatment for a mental illness in a general (Tier 4) adolescent ward, (c) who can communicate in spoken English.

There were no exclusion criteria relating to the participants. There were several criteria relating to the participants’ children, however, some of which were by default due to the nature of the sampling strategy and research question. For instance, the criteria for admission into a Tier 4 ward (NHS England, 2018) meant that the child would, by nature of Tier 4 inclusion/exclusion criteria, be between the age of 11-17 years, and would not have a primary diagnosis of an eating disorder, conduct disorder, substance misuse, severe autism or a learning disability. A secondary/comorbid diagnosis of these disorders was acceptable, however.

An additional requirement relating to the child was that the child must have been an inpatient on the ward for a minimum of ten days at the time of the parent’s interview. The rationale for this was that as participants were to be interviewed about the experience of being a parent to a child in inpatient CAMHS, they needed to have had some time to adjust to and make sense of this experience, and this was less likely to have occurred if the child had been only very recently admitted to the ward. This ten-day period gave parents time to begin adjusting to their circumstances and to experience many typical inpatient events such as interacting with staff members, receiving feedback from a ward round, and speaking to or visiting their child on the ward, for example.

Finally, a grace period was granted to allow for parents to be interviewed within ten days of their child's discharge or transfer out of the ward, in cases where it had not been possible to schedule the interview during the child's admission. The rationale for this was that admission into a psychiatric ward can be transient for several reasons. Occasionally, young people may be discharged within days of their admission, or they may be transferred to a more suitable service when a bed becomes available, such as being "stepped-up" to a more secure ward, transferred to adult services if nearing their 18th birthday, or transferred to a ward closer to their family home. This ten-day grace period therefore meant that if a parent had scheduled an interview, and their child was then unexpectedly discharged/transferred out of the ward, the interview could still be conducted within this short space of time. However, parents would be excluded after this ten-day period had passed as they would be more likely to have had experiences post-discharge/transfer that may have changed the way they reflected on the admission itself. It was important that the interviews focused on experiences during the admission, rather than the experience of discharge/transfer or of adjusting to the child returning home. However, this grace period was not required by any of the participants, as all were interviewed while their child remained an inpatient on the ward.

Procedures

Recruitment Procedure

Participants were recruited from five General Adolescent Wards in England, identified through connections with the Doctorate in Clinical Psychology programme at the University of Essex.

During the first stage of the recruitment procedure, the researcher contacted the lead psychologist in each of the five wards and shared a copy of the research proposal. All five psychologists agreed to support the research and permitted the researcher to recruit from their services. The researcher remained in contact with the psychologists throughout the process of gaining ethical approval for the research, and their suggestions relating to recruitment were included in the applications for ethical approval.

A "gatekeeper" was then identified in each of the five wards; this was either the lead psychologist or another member of the staff team who had agreed to support the researcher with recruitment. Each gatekeeper had spoken with the researcher, and understood the purpose and aim of the research, as well as the sampling requirements. Gatekeepers were therefore able to speak with parents who visited their children on the ward about the research, and answer questions. The gatekeeper disseminated information about the research by email to all parents of current inpatients, namely the flyer (Appendix D) and a brief email drafted by the researcher (Appendix E). Parents who were interested in the research were invited to contact the researcher directly by email. Upon doing so, these parents were given further information about the research in the form of the Participant Information Sheet (Appendix F) and they were also given an opportunity to ask questions via email. All parents who expressed interest were also offered an informal phone call, although none took up this offer. For those who wished to participate after receiving the information sheet, interviews were scheduled on a day and time that was convenient for each participant. Participants were asked to return a signed copy of their consent form via email prior to the start of their interview. Participants were given the option of having their interview via videocall or phonecall; all chose videocalls.

Interviews

It was anticipated that in some cases, both parents within a dyad might wish to participate in an interview. Some parents might have wanted to attend separate interviews while others might have preferred to be interviewed together with their partner. This represented an ethical dilemma: if a couple were to be interviewed together, it would require that each parent sacrifice his/her anonymity to his/her partner. However, it would also offer some benefits, as couples attending an interview together would be able to provide each other with support when discussing sensitive issues, and perhaps prompt one another, allowing for rich and interesting discussions. Any of the following arrangements were therefore acceptable:

a) An individual attending an interview on his/her own
b) A couple attending interviews separately
c) A couple attending an interview together.

It was made clear to participants that if they wished to be interviewed together with their partner, each partner would be sacrificing his/her anonymity to the other; participants consented to this in the consent form.

Nineteen parents contacted the researcher by email, expressing an interest in participating in the research. After receiving more information by email, sixteen parents responded and booked interviews. One of these participants then had to cancel on the day of their interview and did not reschedule the interview when prompted by email. The three others who did not arrange interviews after expressing their initial interest were contacted again within ten days of their most recent email, but none of these parents responded.

Data Collection

Thirteen in-depth interviews were conducted, encompassing 15 participants. Nine individuals and three couples took part; of the couples, two were interviewed in their dyads while the third couple took part in individual interviews. All children were still inpatients at the time of the parents' interviews. All interviews were conducted via the videoconferencing software Zoom (Zoom Video Communications, Inc, 2022), and participants were interviewed once only. Interviews lasted between 45 and 138 minutes, with a mean duration of 88 minutes. Only one interview was shorter than 60 minutes. All interviews were video- and audio-recorded, yielding a total of 1,147 minutes of recording.

Interviews were held remotely partly due to constraints around face-to-face contact within the context of COVID-19, but also as online interviews reduce participant demands in terms of time, travel, and cost (Creswell, 2013), and allow for a setting in which participants can discuss sensitive topics more comfortably (Nicholas et al., 2010).

Smith et al. (2009) described establishing rapport as the "most important thing" in research interviews, and stated that without rapport, a researcher is unlikely to elicit meaningful responses from participants. Interviews therefore began with a "warm-up discussion" (Pietkiewicz & Smith, 2014) to put the participant at ease, followed by the collection of basic demographic information (Appendix G).

It can be more challenging to establish rapport in remote interviews than face-to-face interviews. The researcher's own experience of conducting therapy via videocall was helpful, as this experience was drawn upon when attempting to build rapport with the participants over videocall. For example, the researcher was aware that her own tone, language, and non-verbal communication (such as facial expression) would have an impact on each participant's ability to talk about difficult experiences. The ability to come across as non-judgemental was important in facilitating discussions and enabling participants to feel sufficiently comfortable to continue talking, particularly when they became upset in interviews. The researcher had also anticipated that the online medium would mean that it would take more time for participants to feel comfortable, so used active listening techniques and acknowledged participants’ emotions, importantly conveying “empathy and understanding without judgement” (Patton, 2015, p.458). The researcher emphasised that the aim of the interview was to hear about and understand their experiences, in this way adopting a participant-orientated approach, allowing for “smooth information gathering and easier analysis” (Alase, 2017).

A topic guide was used to provide prompts during interviews (Table 4). As noted by Smith et al. (2009), it is unrealistic to attempt to pre-determine interview direction or content. For this reason, the guide contained topics for discussion, rather than lists of pre-determined questions. Every interview started with the same opening question and ended with the same final question. Otherwise, the questions differed slightly in each interview and followed the direction taken by each participant, although the topic guide was used to provide a focus for the interviews.

Table 4

Interview Topic Guide

Topics to Cover	**Question**	**Optional Prompts**
First question:	Can you start by telling me about [child]?	-
Child	-	Noticing child’s difficulties: What? When? Impact on parent
Admission	-	Being away from child – impact on parent Increased or decreased stress? Has it helped child? Visiting child, taking child on home leave Thoughts about discharge
Impact on parent	-	How has child’s mental health impacted parent? How has child’s admission impacted parent? Hobbies, work, social life? Health/wellbeing? What keeps you going?
Impact on relationships	-	Impact on family? Impact on child’s siblings? Do mothers and fathers experience … in the same way? Has your relationship with your partner changed? Can you talk to people about…? Who?
Any other relevant topic	-	-
Final questions:	Is there anything else you want to say?	How has it felt talking to me?

Analysis

The analysis followed the seven phases of narrative analysis outlined by Fraser (2004) and described below.

Phase One: Hearing the Stories, Experiencing Each Other's Emotions

This first phase began during data collection. During the interviews, the researcher paid attention to her own emotional responses to the participants' words, inflections, body language, and emotional states, thereby going beyond the explicit content of the interviews. The use of a reflexive log (Appendix H), kept throughout the data collection and analysis process, also facilitated this reflexive process. The researcher used the reflexive log to comment on the sense she got from each participant and each interview, how interested, curious, surprised, or moved she felt, and hypothesised about the reasons for her own responses to the material. This was an important first step in the process of acknowledging her own active role in data collection and analysis.

Phase Two: Transcribing the Material

The researcher transcribed all interviews herself, considering this to be a fundamental part of engaging with the stories. The interview recordings produced both an audio file and a video with audio file. The researcher chose to use the latter for the purposes of transcription. This had a number of benefits. For instance, during the transcribing process, the researcher had the sense that she was re-experiencing the interviews, along with many of the emotions she felt at the time of the interviews. Having visual content also made the interviews more memorable and allowed for non-verbal communication to be included in the transcripts. As noted by Riessman (1993, p.12), researchers can choose to transcribe with a considerable level of detail, including participants' silences, false starts, and emphases. In order to ensure the transcripts contained as much detail as possible to allow for in-depth analysis, these, and other aspects of participants' vocalisations (laughing, crying, and so on), were included in the transcripts. It should be noted that it is unlikely that all non-verbal cues were noted and accurately transcribed; some are likely to have been missed, and this was a highly interpretative part of the transcribing, and later analytical, process.

Nevertheless, Murray (1999) noted that it is important for researchers to consider that readers actively engage with stories when reading them, which "transforms" the stories. A strength of narrative approaches is that they can make use of longer, more extended "stretches of talk" (Riessman, 1990, as cited in Murray, 1999), but the way in which these are presented in academic narratives may affect how the transcripts are understood. Gee (1991, p.36) wrote that the narrative itself “tells us the terms on which it requests to be interpreted”. While the analysis could have been illustrated with simple methods of transcription, it was considered important to present some excerpts in a way that would convey the tone of the interviews and provide the felt sense of the interviews. Therefore, for a subsection of the transcript excerpts chosen to be presented in the thesis, Gee’s (1986, 1991) poetic structural approach was used as a method of re-transcription. This approach to transcribing interviews can facilitate in-depth analysis of excerpts (Poindexter 2003), but also enhances readability of narratives that might otherwise have been difficult to understand. It has been noted that many researchers use Gee’s (1986, 1991) poetic structural approach to re-transcribe specific excerpts that are of interest within longer interviews (Poindexter, 2003); this is the approach that was taken in the present study. Poindexter’s (2003) method of re-presenting excerpts draws on Gee’s (1986, 1991) method, but with the addition of numbering lines and including a transcription key. A small number of interview excerpts are presented in this thesis using Poindexter’s (2003) method, with the primary aim of enabling readers to “experience the talk” of the participants (Poindexter, 2003). The transcription key can be found in Appendix I.

Phase Three: Interpreting Individual Transcripts

The researcher continued to immerse herself in the data by watching the interviews, reading the transcripts, and reading and listening simultaneously. The transcripts were printed out and annotated during the re-readings. Initially, the researcher highlighted and annotated interesting, surprising, or moving passages. As described in Phase Two, the sense the researcher got from each interview was included in annotations, and in cases where a participant’s tone appeared contradictory to his/her words, this was noted. On subsequent readings, the researcher considered each interview more broadly, identifying themes present in each one.

Narrative theory was brought in during this phase; plots, characters, structures, and storylines within the narratives were identified. Furthermore, Frank’s (1995/2013) narrative types were used to inform the analysis. Andersen and Kragh (2009) note that the use of an existing framework in analysis can form part of the process of engaging “in a discourse with the scientific community”; Frank’s (1995/2013) narrative types constitute one of the key theoretical works to come from recent work on living with illness. Narrative types are described by Frank (1995/2013, p.75) as the “most general storyline that can be recognised underlying the plot and tensions of particular stories". In his work on illness narratives, Frank (1995/2013) identified three narrative types: restitution, chaos, and quest. In restitution narratives, people tell the story of restoring their health, and illness is narrated as transitory (p.115). Chaos narratives, unlike restitution narratives, are difficult to listen to as they are anxiety provoking; narrators cannot imagine life getting better, and the narratives lack the coherence and sequence that usually allows listeners to feel they are hearing a "proper" story (p.97). In quest narratives, people accept their own suffering and believe they can gain something from the experience (p.115). Frank suggested that these three narrative types are to be used as listening devices, and he invited and encouraged others to propose "other types of narratives" (p.76).

Frank's narrative types were held in mind during this, and subsequent, phases of analysis. By using the three types as listening devices, the researcher noted when participants' narratives fitted or did not fit with one of the three narrative types. Thus, the researcher was not "blinded" by Frank's persuasive narrative types, remained flexible in her approach, and was open to alternative interpretations of the data (Andersen & Kragh, 2009). These authors also noted that new theories are developed through engagement with an existing theoretical framework, in which relatedness and incompatibility is discovered, generating new insight. This approach allows for the framework to be held in mind during analysis, whilst other perspectives are considered and accepted or rejected.

Through this process of constant comparison with Frank's narrative types, it was clear that many of the stories told by participants were illustrative of the chaos narrative type. Some stories were suggestive of restitution and quest narrative types, although these were less frequent. However, crucially, many of the stories that were not reminiscent of chaos narratives were also not captured by restitution or quest narratives. The researcher therefore took up Frank's suggestion of proposing other narrative types (p.76) to complement the chaos narrative.

Phase Four: Scanning Across Different Domains of Experience

After each interview had been considered in isolation in Phase Three, this subsequent phase allowed the interviews to be appraised within their wider contexts. As suggested by Fraser (2004), stories were examined for intrapersonal, interpersonal, cultural, and structural aspects. As per Fraser's (2004) definitions, intrapersonal elements of stories involved narrators describing their own thoughts and feelings, revealing inner dialogue ("I said to myself…"). Interpersonal aspects involved narrators describing interactions with other people; this typically included reported speech ("and then he said…"). Cultural aspects involved references to popular culture (including media/news), groups of people, and culturally accepted or sanctioned behaviours or conventions (such as references to "good" or "bad" parenting). Structural aspects included references to ethnicity, gender, disability, socioeconomic status and class, among other characteristics, including when these were described in the context of broader social systems and institutions (such as when narrators spoke about socioeconomic status in relation to access to healthcare).

Phase Five: Linking 'the Personal With the Political'

In this phase, the ways in which participants referred to popular or common discourses were considered. This involved checking for metaphors, sarcasm, and humour, as ways in which discourses can be revealed or concealed (Fraser, 2004). Furthermore, attention was given to what the stories said about participants' lived experiences of gender, race, socioeconomic status and other characteristics, as well as the intersections of these identities and experiences.

Phase Six: Looking for Commonalities and Differences Among Participants

To some extent, this sixth phase was not a discrete phase of analysis but occurred throughout the analytical process. During phases three, four and five, the researcher began to identity patterns including, but not limited to, the characters, chronologies of events, plots, themes, and tones of the interviews. Narrative theory was, again, brought into this stage of the analysis. By looking for commonalities and differences within and across interviews, interviews could be broadly categorised under one of three narrative types. Through further consideration of content and tone of the interviews, the researcher identified a number of themes which could be contained within each of the narrative types. A lengthy process of checking, comparing, and revising these themes continued until the researcher felt that the breadth of experience was captured by the themes, and that these themes illustrated each of the three narrative types.

Phase Seven: Writing Academic Narratives About Personal Stories

This phase involved short-listing stories that convincingly demonstrated a theme or were contradictory, surprising, or interesting. The reasons for short-listing stories were noted in order to promote transparency, as it should be acknowledged that such decisions may be more indicative of the researcher's emotional state and meaning-making processes than that of the participant.

Ethical Considerations

Ethical Approval

Approval for this research was granted by the NHS Health Research Authority (HCA) and Health and Care Research Wales (HCRW) (Appendix J). Ethical approval was also granted by the University of Essex (Appendix K). Ethical approval was obtained before beginning data collection and the research was carried out in accordance with The British Psychological Society's Code of Ethics and Conduct (2018).

Informed Consent

Participants were provided with a Participant Information Sheet (Appendix F). They were then given an opportunity to speak to the researcher to ask questions about the research.

All participants provided written consent to participate (Appendix L); each participant's consent form was received by the researcher, by email, prior to their interview. Verbal consent was additionally gained from each participant at the start of the interviews. Participants were made aware that they could choose to terminate the interview at any time, at which point their interview recording would be deleted, and their data would not be included in the research.

Confidentiality and Anonymity

Participants were provided with information about how their data would be stored, used, and disseminated, as well as the measures that would be taken to maintain their anonymity.

All interviews were conducted by the researcher. Interviews were recorded on Zoom, saved on a password-protected computer, and subsequently deleted from Zoom. At this point, each participant was assigned a unique identification number and pseudonym. This information was stored in a password-protected Excel file, accessible only to the researcher.

All interviews were transcribed by the researcher. During transcription, interviews were further anonymised. Participants were given pseudonyms, and names of any other person or place mentioned in interviews were also changed or redacted. Care was also taken to ensure that any combination of information (e.g. age, ethnicity, child's diagnosis) would not make it possible to identify any individual: minor details were either changed or redacted.

Participants were informed that only the researcher and the researcher's supervisors would have access to the anonymised transcripts in full. Participants were also informed that direct quotations from their interviews would be included in the write-up and dissemination of the research, but that the aforementioned measures would be taken to maintain their anonymity.

Participants who chose to be interviewed together with their partner were advised that they would be sacrificing their anonymity to their partner.

Risk of Harm

The interviews covered a range of topics related to the experience of parenting a child who is receiving treatment in an inpatient mental health service. The discussions therefore covered sensitive issues and there was a risk of emotional distress to the participants.

Participants were informed that they could choose not to respond to any of the questions in the interview and could also request a break at any point during the interview. They also had the right to withdraw from their interview at any time, without giving a reason, and without repercussions.

Participants were informed of the limits of confidentiality: if they disclosed any information that suggested that they, their child, or another person may be at risk of harm, the researcher would have a duty of care to share this information with the inpatient ward. The inpatient wards were aware of this agreement. However, no such issues emerged in the interviews.

Results

This chapter presents the results of the research. It begins with a description of the sample, and the demographic characteristics of the participants and their children are provided. The narrative analysis is then presented, with attention given first to narrative structure, and then to the three narrative types, which constitute the main findings of this research. The three narrative types and their respective themes are explored in detail.

Sample

A total of 15 parents participated in the research. They comprised ten mothers and five fathers from 12 families. Nine people were interviewed individually (nine families), two couples were interviewed as couples (two families), and one couple took part in interviews as individuals (one family). Eleven participants were married and co-parenting their child. Three participants were single mothers, describing themselves as separated (two mothers), and single (one mother). One participant, a father, had separated from his daughter's mother and remarried; he was involved in his daughter's care, but his daughter lived with her mother.

The participants' ages ranged between 41 and 63 years, with a mean age of 50 years. Twelve participants were White British, two participants were Indian, and one participant was Mixed White and Asian; this information has not been included in the demographic table (Table 5) to preserve anonymity, and common, British pseudonyms were chosen for all participants for the same reason. Six parents were in full-time employment, seven were in part-time employment, and two were unemployed. Three participants were signed off from work on long-term sick leave and two further participants had resigned from previous jobs; in all cases these circumstances were related to the demands of caring for their child. In addition to the child on the inpatient ward, all parents had at least one other child. Participant characteristics are presented in Table 5.

At the time of their interviews, participants reported approximately how long their child had been on the inpatient ward. This ranged from 21 days to 210 days, with a mean duration of 109 days. For five parents (three families), this was not their child's first admission to an inpatient ward. There was considerable variation in the amount of contact participants had with their child at the time of their interviews. One parent had no contact with their child. Four parents had fewer than 5 hours of contact with their child each week. Two parents reported having between 6-15 hours and 16-35 hours of contact with their child each week, respectively. Eight participants spent more than 35 hours per week in contact with their child. Contact included phone-calls and video-calls, visiting their child on the ward, or spending time with their child on leave, either in the local community or at home. For those spending comparatively more time with their child each week, this was usually because the child was able to come home for overnight leave at weekends. However, most parents commented that contact with their child varied each week, was dependent on their child's presentation on the ward, and could quickly change.

The duration of the children's mental health difficulties ranged from 1 year to 15 years and they had received a range of psychiatric diagnoses. All children were aged between 15 and 17 years old. Nine of the children were female, two were male, and one child was transgender, identifying as a girl. Table 6 contains more detailed information about the participants' children. In order to preserve the anonymity of the participants, they have not been connected to their child in this thesis; the participant and child ID numbers are unrelated.

Table 5

Participant Demographic Characteristics

ID	Pseudonym	Age	Relationship	Marital Status	Co-parenting	Number of Children	Employment/ Study
1	Beth	47	Mother	Married	Yes	2	Part-time
2	Jack	45	Father	Married	Yes	2	Part-time
3	George	47	Father	Married	Yes	2	Full-time
4	Matthew	63	Father	Married	Yes	4	Full-time
5	Samantha	48	Mother	Married	Yes	2	Part-time
6	Mary	51	Mother	Married	Yes	2	Part-time
7	William	63	Father	Married	Yes	5	Full-time
8	Emily	52	Mother	Married	Yes	2	Part-time
9	Kate	49	Mother	Married	Yes	2	Part-time
10	Chloe	48	Mother	Separated	No	2	Full-time
11	Imogen	50	Mother	Separated	No	4	Part-time
12	Amelia	60	Mother	Married	Yes	2	Full-time
13	Claire	44	Mother	Single	No	2	Full-time
14	Olivia	47	Mother	Married	Yes	2	Full-time
15	Luke	41	Father	Married	Yes	5	Unemployed

Table 6

Child Demographic Characteristics

ID	Age	Duration of Mental Health Difficulties	Diagnoses	Risk Preceding Admission
1	16	1 year	Anorexia Nervosa, Anxiety, Depression	Risk of suicide
2	15	1 year	ASD, Depression	Risk of suicide
3	17	1-2 years	ASD, OCD	Risk to physical health
4	15	2.5 years	Anxiety, ASD, Depression, Eating Disorder, Psychotic Episode, PTSD	Risk to physical health, risk of suicide
5	17	3 years	Anxiety, ADHD, BPD, Depression, EUPD	Risk of suicide
6	15	4 years	ASD, *other diagnoses unknown*	Risk of suicide
7	16	5 years	Anxiety, Depression	Risk of suicide
8	17	7 years	Agoraphobia, ASD, Depressive Episode Disorder, OCD, Panic Disorder	Risk to physical health, risk of suicide
9	17	8-9 years	Anxiety, Depression	Risk of suicide
10	16	9 years	Anxiety, ASD, C-PTSD, Depression	Risk of suicide
11	16	10 years	Depression, Disordered Eating, *other diagnoses unknown*	Risk of suicide
12	17	15 years	ADHD, ASD, Emotional Dysregulation, Sensory Processing Disorder	Risk of suicide

Note. ADHD = Attention-Deficit Hyperactivity Disorder, ASD = Autism Spectrum Disorder, BPD = Borderline Personality Disorder, (C-)PTSD = (Complex) Post-Traumatic Stress Disorder, EUPD = Emotionally Unstable Personality Disorder, OCD = Obsessive-Compulsive Disorder

Narrative Structure

There were temporal similarities in the way participants structured their narratives. Each interview began with the same opening question ("Can you start by telling me about [child]?"), and despite the openness of this invitation to talk about their child, the parents made similar decisions in how they structured their narratives. Although the scheduled opening question used the present tense, most participants began by describing what their child was like when s/he was younger, as though setting the scene for the remainder of their interview (Imogen: "we've always had problems"). All interviews therefore began with a description of events in chronological order, beginning with the years before their child's inpatient admission. Parents narrated pivotal turning points (Mary: "and then, of course, the problem started"); these were often critical incidents which led to their child's inpatient admission, told as the middle of their stories. While all participants described events up to and including the time of the interview, a beginning-middle-end narrative structure was not fully present, as none of the narratives contained endings. This is indicative of the participants' current circumstances, with all parents still in the midst of their child's inpatient admission at the time of their interviews, many of whom were experiencing uncertainty, and unable to imagine what the near future might look like.

The absence of an ending to the narratives, and the ways in which participants narrated their past and present experiences, created a sense of dramatic engagement within the stories. Dramatic engagement was considered by Gergen and Gergen (1986) as "one of the most phenomenologically salient aspects of narrative form: the capacity to create feelings of drama or emotion". Dramatic engagement was considered during the analysis.

Narrative Types

Three narrative types were present in the participants' stories: narratives of chaos, narratives of conflict, and narratives of distance. The chaos narrative type was initially proposed by Frank (1995/2013) in his work on living with physical illness and disease; this was found to capture some of the narratives of participants in the present study. Not all narratives could be captured by narratives of chaos, however, and narratives of conflict and distance are therefore proposed for the first time in this thesis. Within each narrative type, stories were organised around particular themes (Poindexter, 2004) pertaining to the content of the stories. The three narrative types and their respective content themes are presented in Table 7.

In narratives of chaos, as per Frank's (1995/2013) original narrative type, loss of control was apparent. In these narratives, parents often struggled to tell their story, and these narratives were found "on the edges of speech" (Frank, 1995/2013, p.101) in parents' silences, broken-off sentences, and the words they chose not to say. These stories were distressing, with parents describing critical incidents, significant emotional pain, and worries about the future.

In narratives of conflict, parents either described conflictual relationships (with NHS services and professionals), spoke about the differences in how mothers and fathers cope, or narrated in a way that was suggestive of intrapersonal conflict.

In narratives of distance, parents described how although admissions initially provided feelings of respite as their children were no longer at home, this was soon replaced by new, distressing feelings. They described ambiguous loss caused by physical or psychological distance from their child. However, some parents also described distance from events in terms of time, which created a sense that the worst was over, yielding hopefulness. As some parents narrated in a distanced or detached way, this narrative type includes those stories in which participants seemed emotionally distanced from distressing events.

Table 7

Narrative Types and Themes

Narrative Types	Themes
Chaos	Critical incidents No one feels our pain What if s/he doesn't get better?
Conflict	Feeling trapped in an NHS system One of us has to be the stronger one
Distance	Admission provides respite but it doesn't last Ambiguous loss The passage of time

The remainder of this chapter explores, in detail, the three narrative types and corresponding themes. Quotes from interviews are provided in order to exemplify the narrative types and themes, and some more detailed, lengthy excerpts from transcripts are also included, using Poindexter's (2003) adaptation of Gee's (1986, 1991) transcription method. These offer readers the opportunity to examine the narratives and evaluate the researcher's argument independently (Riessman & Quinney, 2005). These longer quotes should also enhance understanding and should provide readers with a sense of the experience of being with each participant (Poindexter, 2003). A transcription key, adapted from Poindexter (2003), can be found in Appendix I.

Fraser (2004) suggested that the criteria for short-listing stories are provided to readers so that readers can consider the reasoning that underpins the work. As such, the criteria for short-listing stories to be included in the write-up of the analysis were as follows:

Stories were shortlisted that either:

a) Demonstrated a theme/narrative type through the words used in the narrative;
b) Demonstrated a theme/narrative type through the way in which the narrative was told;
c) Demonstrated dramatic engagement.

Chaos

This first narrative type reflects the most common type of story told by the parents. Within these narratives, chaos was found not only in the content of the stories, but in the way these stories were told. A crucial feature of narratives within this narrative type is that they appeared to reflect the inner chaos experienced by the parents. Parents struggled to tell these stories; they paused, stumbled over their words, used metaphors or insinuation instead of concrete language, or left sentences unfinished, choosing not to say certain words at all. Tearfulness, unexpected laughter, body language and gesture were meaningful within these narratives. Only a minority of participants were able to narrate chaos stories coherently and in narrative order, demonstrating their ability to reflect on the events and thereby revealing that they were no longer living the chaos.

This narrative type includes three themes within which related stories were grouped. These content themes (Poindexter, 2004) therefore capture the different types of chaos stories told by participants. Firstly, the theme of *critical incidents* contains the stories every participant told of frightening moments in which their child was at risk of harm. The second theme, *no one feels our pain*, reveals the insular and unwitnessed impact on the whole family. Thirdly, *what if s/he doesn't get better?* captures spoken and unspoken worries about the future.

Critical Incidents

Every parent spoke about serious, critical incidents that had occurred in recent history, generally during the days or weeks preceding their child's inpatient admission. These stories typically formed the beginnings of each parent's narrative.

For most parents, these incidents involved their child engaging in self-harming behaviours or attempting suicide:

> And then the third [overdose], she was here, and she took 200 paracetamol […]. We sort of sensed something was wrong anyway, so we was checking on her all day long and then obviously she went to the toilet and came out clutching her stomach. Um, she ended up in HDU is it? With the intubation and that. (Imogen)

Some parents also described incidents in which their child absconded from home or from hospital, requiring police involvement, and they spoke of their child's attempts to resist help from police or medical staff:

> So the police got her, put her in holds, but [child] is like, she's like she's possessed when she's angry and […] kicking, thumping the police, she doesn't care that they're policemen, she just wants, she doesn't know what she wants. (Kate)

These incidents of self-harm, suicide attempts, and absconsion were unanimously distressing for the parents. When describing the time her daughter ran away from home and took a significant overdose, Samantha stated "that's the most scared I've ever been in my life".

In this detailed excerpt below, Chloe remembers how she found her daughter after a suicide attempt. The narrative was embodied, as Chloe acted out both how her daughter looked when she found her, and the way she used her own hands to move her daughter's hair and head. Chloe described:

> 1 Well, what happened
> 2 she was, she was kneeling down
> 3 and her head was forward
> 4 and she had the [ligature] around her neck

5 but because she’s, she’s got long […] hair
6 =so it was sort of all over her face.
7 So the first thing I did I just sort of
8 =pulled her hair back
9 =and then tipped her head back *{demonstrating}*.

10 And it was almost like she’d regressed to being a baby,
11 it was really bizarre
12 =it was like

[Interviewer: what do you mean?]

13 I just sort of looked at her
14 =like she was my baby again
15 even though there was this, I mean
16 when I started trying to lift her, she's [tall]
17 but her face was like a baby

18 and it just sounds –
19 I can't really say –
20 it's just like, like I felt
21 =I had all this responsibility again.

[Interviewer: that's really interesting]

22 yeah yeah I just felt like um, yeah
23 but then once I layed her down
24 =and she started… all her hands started contorting
25 =and she sort of, not fitting, but you could see she was spasming.

26 The paramedics told me why she was doing it, you know
27 =but I still couldn't deal with it

I felt like it was um –
I felt like she was possessed
it was almost like she was fighting herself
=and I think that's how […]
how I sort of think

maybe she was fight –
in my head, she was fighting her demons
and I can accept that her hands were like that
and her body was rigid
but medically you could tell me why it was happening
=and I didn't like it.

So it's almost like
=I've got to give myself a reason
and process it, yeah.

Chloe was the only parent who spoke about having her own therapy for PTSD; she had been experiencing flashbacks in the aftermath of finding her daughter unconscious. Chloe said that this therapy had "helped [her] massively because [she] couldn't talk about it before". Through telling this story multiple times (Chloe went "over and over it" with her therapist) she seemed to have been able to turn her chaos into a story. Chaos narratives are unique in the way that a true chaos story cannot be told through words, as "lived chaos makes reflection, and consequently storytelling, impossible" (Frank, 1995/2013, p.98). This narrative therefore stood out as Chloe was able to retrospectively reflect on the event; she was no longer "living the chaos" (Frank, 1995/2013, p.98), and yet her story tells of the chaos she experienced, with her struggle to understand and make sense of what she was seeing at the time. Just as chaos may make it impossible to tell a coherent story, the ability to tell a story is thought to "neutralise" chaos (Frank, 1995/2013, p.105). Chloe demonstrated this in her interview; the coherence of her story, which was chronologically ordered and narrated clearly and calmly, intimated that she was describing the chaos from outside of it.

Unfortunately, for many parents, critical incidents did not stop when their child was admitted to a ward. For most, their child continued to engage in self-harming behaviours whilst on the ward. Parents were updated about these incidents by staff members who phoned them at home. This had a detrimental impact on parents’ wellbeing. Imogen explained “as soon as it comes up ‘no caller ID’ I expect the worst”; she had learned that phone-calls usually meant bad news, and went on to describe the impact of the calls:

> I don't think I slept probably for about three or four weeks when she was first in there, because I kept imagining things happening, and I was literally waiting for the phone calls all the time, when she was kicking off and then she was being injected to calm her down and different stuff. (Imogen)

Imogen was not the only parent who described how these phone calls impacted sleep. William and Emily had a conversation about their experience of receiving phone calls at night:

> *William:* And you know, we’ve got to go and work as well, and you wake up, and you’re buzzing, you’re wide awake all of a sudden, and you’re too tired physically to get up and go down the stairs, but you’re not tired enough mentally to go back to sleep, cos you’re thinking: what’s caused it? Why has it happened? And cos the incidents are far more now than ever at home. Far more […]
>
> *Emily*: As soon as I hear the phone ring now, when I get woken up by the phone, as soon as I hear it ring, I’m like: it’s the ward, she’s had another incident.

Emily went on to explain that she had since asked the ward not to phone her between midnight and 7am. She remembered asking the staff: “can you please allow us one night of sleep?”.

Similarly, other parents had found that the only way they could sleep was if they were uncontactable at night. Mary said: “I’ve actually had to… I leave my phone downstairs, I don't want to know, we’ve turned the landline off because at least when I go to sleep, I can't be…I just can’t…”. Mary was also looking forward to an upcoming holiday, and hoping to experience some respite, but was concerned that the need for her to be contactable while abroad would impact her ability to relax. She said: “I don't know if I'm going to be able to properly switch off as long as I’ve got a mobile phone”.

No One Feels Our Pain

This theme depicts parents' sense that their pain and suffering was not recognised or understood by anyone outside of their immediate families.

All participants had at least one other child in addition to the child on the ward. Parents therefore spoke about the impact on the family system; families were described as "broken" (Amelia) and "fractured" (Olivia). Olivia explained why: "the family obviously is quite fractured because, you know, [child] isn't at home at all, so, you know, we've got one bedroom that's empty all the time".

The name of this theme was taken from Beth's interview. In the following three-minute excerpt, Beth's pain was unmistakable. This narrative captures the impact of her son's illness and admission on herself and on her family, and her sense that this is not recognised by others. It is also demonstrative of the difficulties of telling a chaos narrative.

1 We want to take him out from there,
2 but, honestly I,
3 we also talk to other people,
4 and we also previously
5 =we don't want to make any complaint,

6 but now I realise that
7 it's time to tell other people
8 because, it's not only,
9 it's, it's justice for
10 =not only justice for [child],
11 this is also *{pause}* pain of other patients and their parents!

12 We, not only [child],
13 the WHOLE family is affected!
14 I have 11-year-old daughter and *{voice breaks}*
15 she is a biggest sufferer! *{pause} {swallows, looks down, takes deep breaths}*

16 Initially, when we cried a lot,

17 many times she told
18 “don't cry mama, *{voice breaks}* stop crying” *{pause}*

19 And *{shaking head}* we do not have any extended family members,
20 that I can send her somewhere *{voice breaks}. {pause}*
21 And *{shakes head, eyes closed}* no one feels our pain. *{pause} {cries, takes deep breaths, looks away from camera and wipes eyes}*

[Interviewer*:* What you're touching on there is the thing I'm most interested in this research, it’s the pain of the family]

22 Yeah. It’s *{pause} {continues crying, takes deep breaths, looks away from camera}*
23 and I realized after,
24 when my son going through this tough time, *{pause} {takes a deep breath, wipes eyes}*

25 it's actually changed MY life!
26 I learned a lot!
27 My life changed! *{looks away}*
28 I want to do something, *{voice breaks}*
29 I want to achieve something *{cries, places head in hands, takes deep breaths}.*

30 But I,
31 now I realise that nothing is *{pause}*
32 nothing can give you happiness
33 if you want to be happy. *{pause} {catches breath, tearful}*

34 And, I,
35 now I tried because *{pause}*
36 what I realise,
37 I don't know any day he can achieve

38 =still I believe, if he gets chance
39 he can achieve many things.

40 But just after=before lockdown,
41 I can see his dream,
42 and now
43 his dream is almost gone! *{continues crying, covers face with hands} {long pause}*
44 And now
45 =I am scared to encourage my daughter to do something *{pause}*. *{cries}*

While English was not Beth's first language, her speech was often organised and coherent in her interview, and she expressed her thoughts and feelings imaginatively and with detail. This makes the syntactic structure of this excerpt remarkable, with its clipped, disjointed phrasing and its sentence structure indicative not of her command of English, but of the chaos that made it difficult to narrate. In the final three stanzas, Beth interrupts her own speech with "but I" (line 30) "and I" (line 34), "and now […] and now" (lines 42 and 44), typical of the chaos narrative type in which the narrator interrupts herself as she tells her story (Frank, 1995/2013, p.105). These interruptions, rather than slowing her down, increased the tempo of this narrative, as though alerting the listener to the urgency of her story, and providing the listener with a sense that there is more to be told.

The dialogic nature of this excerpt is also notable. The interviewer said very little throughout the interview, despite it lasting over 90 minutes. However, in this extract, between lines 21 and 22, Beth paused and looked away from the camera and appeared to be trying to compose herself, and at this point the interviewer entered into the dialogue. The interviewer revealed that she could recognise Beth's pain ("the pain of the family"), in contrast to Beth's sense that "no one feels [their] pain" (line 21). This was important in encouraging Beth to continue, as although the anxiety that chaos narratives create typically inhibits hearing (Frank, 1995/2013, p.98), the interviewer demonstrated some understanding, as well as willingness to hear Beth's story, giving her permission to continue ("the thing I'm most interested").

This perhaps enabled Beth to work up to the final line of this excerpt (line 45). She began speaking about her daughter in line 14, and this was the point when Beth became overcome with emotion. Thinking about the impact of her son's illness on her daughter caused significant emotional pain, and Beth subsequently did not speak about her daughter in the final five stanzas, with the exception of the last line (45). This final line connected with Beth's earlier comments about her daughter and connected the interwoven stories within this short narrative (seeking justice, experiencing isolation, searching for happiness, experiencing worry, grief, and pain), ultimately representing the impact of her son's illness and admission on the entire family.

Like Beth, many of the parents felt that other people did not understand how painful and difficult their lives had become. There was a sense that family members and friends could only understand if they had first-hand experience. Some people, such as Imogen, considered themselves lucky to have close friends or family members who were supportive, but Imogen also described her "breakdown", and her amazement that strangers' lives could carry on as normal, despite the emotional turmoil she was experiencing:

> I just stood in the middle of our local shopping centre and everyone around me was all buzzing and happy, got their wrapping paper, got this, got that, and I just looked around, and I was like "why, why are you all smiley?". And I just stood in the middle of the centre and just cried my eyes out, just like "why are you all carrying on with life like it's normal? It's not". I didn't even know if I was going to see my daughter [on] Christmas Day. (Imogen)

What if s/he Doesn't Get Better?

This theme captured the worries that many parents struggled to voice in their interviews. It was common for parents to plainly express their worry that their child might not recover, while the implication was the worry that the absence of recovery would mean death. The name of the theme comes from Mary's interview.

Mary explained that the outcome of the "constant strain" of caring for her daughter was a panic attack which left her recovering at a friend's house for a week. She described the impact of worrying about whether her daughter would survive:

1 It's just I'd been under
2 =that constant strain of
3 am I going to find her – *{pause}*
4 what's she going to do next –

5 does this mean –
6 is she alright –
7 do I need to go and check on her –
8 just that whole 24 hours a day thing
9 =the pressure

The rapidity of Mary's speech in this extract evoked the "pressure" she described experiencing herself (line 9). Her speech felt pressured as she quickly voiced the five questions she had been asking herself. Mary left two of these questions unfinished (lines 3 and 5), cutting each question off and chasing it immediately with a new question, driving her speech forward even more quickly. In line 3 in particular, Mary appears to be alluding to her fear of finding her daughter dead. Consistent with a narrative of chaos, her strain and suffering are captured by the absence of words; her inability to voice the questions in full portrays how unspeakable these fears are.

In a similar manner, when speaking about the experience of her daughter having overnight leave from the ward, Emily's choice of words was notable:

1 We worry
2 while she is in the house, you know
3 lying there
4 and it sounds really bad but
5 =in the morning when I get up
6 going to her room
7 making sure she's still there? You know
8 =opening that door, to think
9 is she still in her bed?

Emily reflected that she knew these worries are not usually spoken or acceptable (line 4), and then phrases her fear as though it is a question (line 7), as if she was "trying it out", unsure whether it was permissible to say it aloud. Emily seems to be expressing her concerns that her daughter might have absconded during the night (lines 7 and 9), but the unspoken worry is whether or not her daughter would still be alive, as her daughter's previous absconsion attempt led her to a bridge with the intention of jumping. "Still there" (line 7) evokes the idea of death and seems to be a euphemism for this worry which she cannot say aloud.

Other parents spoke more explicitly about death. Samantha described feeling scared: “scared going in her room, because [of] not knowing whether she’s going to be alive or dead”.

Most parents spoke about how difficult life had become prior to their child’s admission. Parents’ lives were severely compromised in their attempts to keep their child safe:

> It had become like a living hell. Because obviously we couldn't have anything in the house that she could harm herself with so everything was locked away, um, had to keep the door, front door locked, we got extra locks put on the front door so she couldn't access the road. (Olivia)

Parents reflected on these circumstances and realised that they could not live under such challenging circumstances again. This amplified their need for the admission to help their child and led them to worry about how they would cope if their child did not get better. Olivia continued: “once she's discharged it all begins in earnest again. So yeah, I’m well aware of what might be coming”.

Conflict

As with narratives of chaos, narratives of conflict manifested in a few ways, as participants’ stories contained different types of conflict which were revealed and expressed in different ways.

Firstly, interpersonal conflict was most apparent when parents’ narratives contained reported speech, providing insight into their relationships and interactions with NHS systems and staff members. These relationships, often highly conflictual, were captured by the theme *feeling trapped in an NHS system*. Secondly, conflict narratives also captured the differences in how parents related to events and circumstances. Mothers and fathers, for instance, spoke about the ways in which their experiences differed from one another. Within these narratives, parents explored contrasting experiences, contained within the theme *one of us has to be the stronger one*. Furthermore, in some instances, analysis of the way in which some parents told their stories highlighted intrapersonal conflict. Parents reported conflicting emotions, responses, and experiences, and some narratives also suggested internal conflict when parents “admitted” to their own thoughts and feelings. These intrapersonal aspects of the narratives feature within both themes.

Feeling Trapped in an NHS System

For all parents, NHS staff and services featured as important characters in their narratives. Although parents were not asked about experiences of general hospitals, many described their experiences of children’s wards in general hospitals; these admissions typically occurred while their child waited for an appropriate CAMHS inpatient bed to become available. Many of the parents began their interviews by describing these events chronologically, and difficult experiences in general hospitals set the scene and were followed by difficult experiences in inpatient CAMHS. Parents described feeling as though they were trapped within the healthcare system – needing the help, but not finding the help sufficient enough to enable them to leave the system. Conflict was the core narrative within these stories.

Mary described her feelings of helplessness with the NHS system, which arose during her struggle to get her child admitted to inpatient CAMHS. She found that “the goalposts [were] constantly changing, [it] felt like people were just making it up as they went along”. She explained:

> It is the most soul destroying, frustrating path I have ever been down […]. Nothing has ever, ever come close to that feeling of trying to get help for your child, and trying to convince some people, a mental health team, that your child desperately needs that help, and the realisation that the help isn't coming. (Mary)

Other parents used descriptions of inappropriate admissions to general hospital to juxtapose their more positive experiences of inpatient CAMHS; Jack described these two experiences as “chalk and cheese”. The experience of general hospital was described by Jack as a “complete nightmare” as the environment was unsuitable and the staff were not trained to support children with mental illnesses. He directly contrasted this to his experience of inpatient CAMHS, in which he said his daughter was “absolutely, you know, receiving the treatment she needs. There's very strong parental involvement and feedback and communication. And it's great”.

Several other parents, however, were concerned that their child had deteriorated during the course of their admission:

> The thought that, you know, my beautiful, super clever, super creative, incredible, wonderful daughter has been through all of this and to the extent that, you know, she's having multiple risk incidents at the moment because she's got no hope because that's what this has done to her, you know, her CGAS scores are half what they were when she was admitted, and you know it was bad enough, then. (Amelia)

Furthermore, holding a belief that the admission was not helping their child seemed to create uncomfortable feelings towards the inpatient wards and the NHS more generally. Yet, even when parents thought that the admission was not helping their child, they also did not believe that other options were available, meaning that many of them described feeling stuck or trapped. The name of this theme comes from Beth's interview; Beth's son was academically gifted, but she described how a label of mental illness kept him stuck within NHS services and prevented him from moving on. She spoke about her son being “tagged with NHS”, alluding to the stickiness and longevity of labels of mental illness. She spoke of discrimination from schools, a significant cause of distress for her family: “now we realize that we are trapped in an NHS system. Because he [is] stuck, he has a mental illness, now all schools reject him because he has [a] mental illness”.

For other parents, while they accepted that their child needed to remain in hospital for the time being, they nonetheless held conflicting views; admitting their child to an inpatient ward was an unsettling experience. Mothers, in particular, described feelings of conflict which arose when they believed that they knew their child better than anyone, but still felt they had to entrust their child to the care of the ward:

> Now we're actually going through this process and seeing how broken this process is as well, you begin to think, which is the worst thing: even if she does get discharged is she going to be safe? Are these people, whoever they are, going to be able to look after her? Because they're not going to know her like we do. (Amelia)

Parents yearned for normality and for a way out of the NHS system. Some parents, like Chloe, alluded to difficult feelings about their child or about the situation they were in. In the following extract, Chloe's use of the words “any of this” are ambiguous; the thoughts she describes appear to be a source of inner conflict. Such thoughts and feelings were not easy for parents to disclose:

> The impact on me, I get very, every now and again, I just want normal. You know, I feel cheated, I've always been, um, a loyal person and an honest person, I've always been kind to people, I've always gone above and beyond, I've always worked hard, I don't, I just think I don't deserve any of this. You know, so I do feel every now and again I get a little bit low, have a little cry. (Chloe)

A minority of parents spoke very candidly about their conflicting thoughts and feelings, and of the painful impact of acknowledging these. Claire, when asked what it was like to be separated from her son by way of the admission, became upset when she disclosed her feelings:

> It's quite… it feels awful. This is where I cry *[begins to cry]*. But actually, it's nice having a rest… because I'm not a hundred percent on it all the time, and I feel really guilty feeling like that *[continues to cry]*, because I love him and I want him home, but actually, it's nice feeling that I've got a bit of normality back, because I haven't had that in years. So yeah, it's quite… guilt, yeah, I feel quite a bit of guilt about that. And, yeah, so that's hard *[pause]*, but yeah, the sort of the "rest" is nice, but it's not, it sort of comes with feeling bad about it. (Claire)

One of us has to be the Stronger One

While it was not necessarily a source of disharmony for couples, mothers and fathers did describe contrasting views and experiences, showing there to be a degree of conflict between their experiences. The name of this theme comes from Samantha's interview. She was interviewed with her partner, Matthew, and described how the way she copes differs to how Matthew copes; "I just think it's my way of coping, and it's almost like I just shut myself off from anything else and just try and be, you know, as practical as I can". Samantha explained that if she didn't do this, she would "probably collapse on the floor and be a complete wreck, you know, I think the way it works, one of us has got to be the stronger one".

Even though all parents who reflected on similarities and differences between mothers' and fathers' experiences felt that parents worked towards the same goal, it was also not unusual for parents to concurrently feel that they were doing things on their own, exacerbating feelings of isolation and loneliness. Matthew and Samantha reflected on the impact of their child's illness and admission on their relationship:

> *Matthew:* The whole thing is just so stressful; I'd defy any couple in our situation for it not to put a strain on the relationship. Not because, you know, obviously we both want the same outcome at the end of the day, you know, we both want to see her better, on a road to recovery, being able to look after herself, etc., etc. So obviously we both want the same end game out of it but…
>
> *Samantha:* But it is, you know, we, as we've said, we deal with things differently, and we've been on different paths, and that is quite lonely.

Five fathers participated in the research; three attended interviews on their own, and two were interviewed with their female partners. All of the fathers interviewed described differences between their experiences and those of the mothers of their children. Gender norms were openly acknowledged by some of them. Jack, for example, explained: "I'm more of a sort of a practical person, let's get stuff done, I guess [wife] is more on the emotional side, but then that's probably quite, quite similar [*laughs*] I mean, how blokes are".

George's experience was similar: "because she is his mother, you know, she will react most, I mean, she will, she will be most in a reactive mode, but I will be most responding more, do you know, so I take time, think, analyse". He continued by referring to gender norms: "mother, she's behaving exactly what mothers [are] supposed to do, or mothers do actually, so it's just being a mother and father that you're […] different".

William and Emily reflected together about whether their experiences were different. They agreed that they were affected in the same way, but that Emily was "stronger". Another father, Matthew, also acknowledged that he was more emotional than his wife, and, unlike his wife, he tended to "fall apart". The fifth father, Luke, was no longer in a relationship with his child's mother. He found it frustrating that he was not sufficiently included in communication from the ward about his child, often not being informed when his child had had an incident on the ward. When asked why he thought this was, he also acknowledged gender, remarking:

> Because she lives with mum, because mum's next of kin maybe? Because I have a penis? I don't know *[laughs]*. It literally is ridiculous, though, um, I have had to tell them in meetings, I've told them on visits numerous times, and it probably took four or five attempts. (Luke)

Parents described differences between their experiences and those of other families. Jack spoke about going on holiday, allowing him and his wife to be "normal parents" again who could "do something normal", an experience they were unable to have prior to their daughter's admission. Another father, George, used the same language when talking about his relationship with his wife, although he contrasted it to that of a "normal couple", noting that, unlike him and his wife, normal couples could "go to the movies".

George said that the challenges the family were experiencing had brought him and his wife closer together. Rather than experiencing conflict within their relationship, they turned their attention to fighting for their daughter:

> My perception is that we are much closer and much stronger in [our] relationship than ever. And that is because we are, we are fighting for one thing, you know, so that's why we have the same goal. Only one goal now. (George)

Distance

This third and final narrative type explores distance: actual and perceived, physical and psychological, and conscious and unconscious.

Generally, physical separation and distance from their child meant that parents experienced some respite, although for most parents, this was soon replaced by other forms of stress. These experiences are explored under the theme *admission provides respite but it doesn't last*. Within the second theme, *ambiguous loss,* parents experienced their child as both absent and present simultaneously. Some found that despite physical separation from their child, the child was always on their mind, while others felt psychically distanced from their child, even when they were together. Finally, the third theme, *the passage of time,* explores how some parents had benefitted from time elapsing, creating a sense of distance from distressing events, and making room for hopefulness about the future.

Within the three themes, the ways in which parents distanced themselves from their own emotional pain are also considered through analysis of how they told their stories.

Admission Provides Respite but it Doesn't Last

The ways in which an admission impacted parents' wellbeing were diverse, and this theme encompasses the varied experiences. It was typical for parents to experience relief at the start of their child's admission. They told stories of the hope they held at this time and the relief they experienced when they had time to themselves for the first time since their child's mental health had deteriorated. Unfortunately, for most parents, this respite did not last; Mary explained that "the relief kind of wears off". Emily reflected on how prior to her daughter's admission, she thought the circumstances she had been dealing with were stressful, but that since the admission other significant stressors had emerged. She said of her daughter's admission: "all I've been doing […] is fighting her battles for her to try and get what she needs". Another mother, Chloe, had been granted long-term sick leave from work by her GP. Since her child had been admitted to the ward, she had extended her sick leave, as rather than experiencing lasting respite which might have enabled her to return to work, she "just spent every day fighting for [child]". She reflected that when her first period of sick leave was coming to an end, she realised she was not ready to return to work. She remembered thinking: "I haven't processed this myself yet, I need a break, I need…".

Jack had a different experience. When asked whether his daughter's admission had reduced his stress, Jack said his stress had "vaporised". For him, the admission had provided him with a strong sense of respite for the first time, following a series of highly stressful events which preceded his daughter's admission. Jack was able to go on holiday with his wife shortly after their daughter was admitted, allowing them to "do something normal".

However, Jack's was the only narrative which described complete stress relief as a result of the admission. The four other fathers had different experiences; Matthew found that both his social life and work life were negatively impacted, Luke was no longer working, George found that his "extreme sadness" made it difficult to contain his emotions, and William was struggling to sleep:

> Sleep-wise, I don't sleep a great deal, I've always got like one eye open, and one ear open, for the phone, I think. I'm used to shift work, done it for years, but I'm feeling more tired now, like right this minute I could go to sleep. I am so tired. (William)

Jack’s contrasting experience may be reflective of his coping style. He appeared to have been able to create some distance between himself and his difficult experiences. For instance, there were moments in his interview in which his tone did not match the content of his narratives, which suggested some emotional distance from his experiences. He described having had concerns that his daughter “was going to try and kill herself every five minutes”, but said this in a matter-of-fact way, which seemed in contrast to the gravity of this statement. Similarly, when describing how looking after his daughter prior to her admission had been a “full time job”, he explained that this was because he had to watch her constantly in case she “might try something stupid”. This language was juxtaposed with the significance of the incidents he had been describing, including his daughter attempting suicide at home.

When asked how his daughter’s suffering and admission had impacted him as her father, Jack briefly laughed. It is possible that the question had touched on a difficult feeling, and his laugh reflected his raised levels of anxiety, and the difficulty of connecting with painful feelings. Many parents appeared to use laughter in their interviews in similar ways. Jack then proceeded to describe two ways in which he had been impacted. He chose to speak first about the positive impact on his relationship with his wife, and secondly of his own optimism: “but, I mean, how's it affected me, I'm, I'm always a kind of more of an optimist, so I just see this as a hurdle that [child] has to get through”. His own optimism was reflected in his answer to the question, as he chose to reflect on how his relationship with his wife had been strengthened. This optimism was perhaps allowing Jack to create distance from his difficult experiences, enabling him to cope. Furthermore, while still responding to the question of how he had been impacted by his daughter’s illness and admission, he spoke about his other child: “on the plus side, my other daughter is absolutely thriving, she's doing brilliantly well”. In this moment, focusing on his other daughter appeared to be another way in which Jack could create distance from painful emotions, and focus on the aspects of family life that were going well.

Jack’s emotional distance from distressing experiences was perhaps a coping strategy that allowed him to experience longer-lasting respite during his child’s admission. He was the only parent who felt his child’s illness and admission had not impacted the family as a whole, and the only parent who described complete stress-relief as a result of the admission. It is possible that his positive outlook and ability to distance himself from painful emotions enabled him to perceive the admission as a positive experience, and experience respite as a result.

Ambiguous Loss

This theme captured the ambiguous loss that parents experienced as a result of their child's deteriorating mental health and inpatient admission. Many of the parents noted that despite physical distance from their child, their child was always on their mind. Others felt that their child's absence had caused them to lose their identity as their child's parent. A minority of parents were not able to visit or speak to their child, and they had sought ways to feel emotionally connected to combat the loss they were experiencing. These, and other types of ambiguous loss, are explored within this theme.

The physical absence of their child was obvious and could not be ignored by parents; Mary described how "it's always there in the background, it's always the elephant in the room". Some loss was experienced as tangible; William noted "she's not here, the presence isn't here, if that makes sense", and Olivia likened the physical loss of her daughter to death: "there's always one bedroom that's empty. And there's always one spare chair at the table, and it is like she's died, you know, it's like she just doesn't exist, sometimes, so it's very, yeah, it's very hard".

Other losses were less tangible. William commented on a different type of loss in relation to his child; he felt that he had "lost [his] voice in how things are going for her". Samantha had noticed that she was no longer engaging in typical mother-daughter activities and described how the separation and distance from her daughter meant loss of her identity as a mother:

> I struggle, because obviously she's not been at home for, a year, you know, coming up to two years, so I really struggle to see myself as her mum, and I think… and to parent her, and to know, you know, what to say to her now. (Samantha)

For some parents, loss was amplified when their child declined to have contact with them during their admission. This was experienced by these parents as highly distressing. Olivia's daughter did not speak to her and her husband for a number of weeks at the start of her admission. She described the visceral impact of this loss:

> [It was] horrific, because, you know, I feel like I've given everything to this now, you know, I've just, yeah I couldn't do, I don't think I could do any more, I'd made myself really ill when we came out of [general hospital] I ended up

> spending two weeks in bed, because my entire insides stopped working, so I became massively…well I won't go into it, but it was horrific. So I mean it's nearly killed me, to be honest. (Olivia)

Matthew and his daughter did not speak for several months. He was so affected by this distance from his child that he would drive to the inpatient ward and stay outside “just to be close to her”.

George was another father who did not have contact with his child. He explained that prior to his son’s admission, his son’s illness meant that he was not responding well to George’s presence at home. George had made the decision to begin sleeping and “living” downstairs, while the rest of the family slept in their bedrooms upstairs. At the time of George’s interview, his son had been an inpatient for several months, but George explained that he continued to sleep downstairs and avoided going upstairs. When asked what it was like to live downstairs, George explained how his son was always on his mind:

> 1 I want to just feel that, you know, I mean
> 2 it makes me more sad
> 3 when I am near the, his room
> 4 it reminds me
> 5 =also those feelings
>
> 6 at the same time
> 7 when I’m living in the living room
> 8 still it reminds me, I mean *{sudden laughter, throws hands into the air}*
> 9 there is no, no escape.
>
> 10 Um, yes, I am happy with it, at least *{pause, looks away}*
> 11 it’s, I'm happy with it
> 12 I mean I’m, I’m enjoying the sadness
> 13 and that's it, I mean.
>
> [Interviewer: You said you're enjoying the sadness]

Yeah enjoying the sadness means
I am, you know
sometimes when you are really sad, I mean
there is a reason to be sad
I think it is better
to BE sad then.

In this excerpt, George described how despite the physical separation from his son caused by the admission, and psychological distance caused by his choice to sleep downstairs, his son was always on his mind. Throughout his interview, George showed attentiveness to his own feelings; he warned the interviewer at the start of his interview that he might become tearful, and, later, talked about how he was using laughter in his interview to “revive” himself, describing it as a “trick” to hide his sadness. This excerpt demonstrated George’s willingness and capacity to acknowledge and experience his painful emotions. Elsewhere in his interview, he described how he deliberately devoted time to thinking about his son and feeling his own emotions, even though this was exceedingly painful for him. George was not able to speak to his child or visit his child on the ward, and so was perhaps managing the painful separation in this way.

The Passage of Time

For some parents, the passage of time had afforded them distance from many of the distressing experiences that had occurred prior to, and during, their child’s inpatient admission. This meant that these parents had a sense that the worst was over and that their child was getting better. Positive, supportive relationships with staff members, a strong couple relationship, and improvement in their child’s mental health appeared to enable parents to tell these stories. Hope for the future was evident in these narratives.

Jack was one parent whose child had made a “significant improvement”. Unlike the majority of participants, Jack had “nothing but admiration” for the inpatient ward staff. He said “we have total confidence in the [ward] staff and, and what they’re doing there”. Furthermore, Jack described a supportive relationship with his wife; “we support each other, and it has really worked, I mean we've always been a good team, but this has really forced us to become an excellent team”. Perhaps as a result of these factors, Jack held the following, optimistic view: “I mean she’s still got a long way to go, you know that was made clear to us, but equally they’ve, you know, she’s made it”.

Other parents had become accustomed to their circumstances, and this created some emotional distance from events that would once have been experienced as distressing. One father described his experience:

> To start with, it used to be, it was very upsetting, I'd feel… come off the phone feeling completely empty, like someone had punched me in the chest, is probably the best way to describe it. And then, after while it became… I don't know, you'd see, I'd see "private number" come up on my phone and I… and my heart would drop. And then you'd get, usually kind of get the same thing, and it got to the point where it was, it became quite normal to get a phone call, which sounds terrible. But it became quite normal to get a phone call maybe once or twice a week saying that… and it was always the same. (Luke)

Samantha described a similar experience, stating "I think I've become immune to it almost, it's almost, you know, it's just another incident, and, which we'd need to deal with".

For parents whose children were not showing signs of recovery, moving forward felt impossible. Emily and William's daughter had been on the ward for a number of months, and they had not been able to visit her on the ward due to restrictions caused by COVID-19. Emily said "life can't be normal again 'til she is home". Another parent, Luke, found it difficult to imagine the future and chose instead to focus on the present: "I mean when I look, you know, like I said, if I allow myself to focus on the, the end game too much, it, it feels too far away to be honest, at the moment".

Discussion

This chapter critically considers the results of the research. The chapter begins with a brief summary of the results, before the narrative types are discussed in more detail and in relation to relevant, existing literature. Critical reflections on the research process and the role of the researcher are then offered. The remainder of the chapter considers the limitations of the research, the implications of the results, and provides suggestions for future research. The chapter ends with a brief conclusion.

Summary of Results

It has been argued that family systems and social-ecological models should be applied by clinical psychologists to understand families of children with chronic illnesses (Kazak, 1989). Family systems theory would emphasise that change in any individual member of a family will evoke change in others (Kerr & Bowen, 1988); when one family member experiences emotional distress, the family system will be disturbed (Bowen, 1978). With this in mind, the importance of considering the impact on parents when a child is unwell has been recognised somewhat, with a small body of research on the experiences of parents who have a child with a disability. Few researchers have considered subjective parental experiences in the context of a child with a mental illness, and the existing studies generally involved the parents of adult children or were conducted in outpatient treatment settings. A gap in the literature was therefore identified: no research had explored the experiences of parents who have a child who is receiving treatment in an inpatient child and adolescent mental health service. As such, the aim of this research was to explore the subjective experiences of parents of children who are receiving treatment in inpatient child and adolescent mental health services in the UK.

This research comprised in-depth interviews with fifteen parents, who chose to be interviewed alone or with their partner. Each of these parents had a child in an inpatient CAMHS ward at the time of their interview. The narrative analysis of these interviews resulted in three narrative types which reflected the types of stories told by the participants: narratives of chaos, narratives of conflict, and narratives of distance. Eight themes were developed and contained within the three narrative types: critical incidents, no one feels our pain, what if s/he doesn't get better? (chaos); feeling trapped in an NHS system, one of us has to be the stronger one (conflict); admission provides respite but it doesn't last, ambiguous loss, the passage of time (distance).

This thesis proposes that the product of this research, the three narrative types, offers contributions to narrative theory, to the literature on family caregiver experiences, and to clinical practice. These contributions will now be explored in the context of a critical appraisal of the research.

The Narrative Types

The chaos narrative type was initially proposed by Frank (1995/2013) in his work on living with physical illness and disease and this was found to capture many of the narratives of the participants in the present study. However, not all narratives were narratives of chaos, and many were also not representative of Frank's (1995/2013) restitution and quest narrative types. Restitution and quest narrative types were therefore not used in the presentation of the results of this research. Instead, the new narrative types of conflict and distance were proposed for the first time in this thesis. As such, the participants' stories were contained within three narrative types: narratives of chaos, narratives of conflict, and narratives of distance.

Although Frank's (1995/2013) restitution and quest narrative types did not feature in the research, these are discussed below. These are discussed in order to consider why these types were not found in the data, and to attend to how this research thus supports other studies in which authors had similar difficulties reconciling restitution and quest narratives with their data. Chaos narratives are then discussed both in relation to Frank's (1995/2013) work and the present research. Subsequently, the new narrative types (narratives of conflict and narratives of distance), proposed for the first time in this thesis, are discussed. Readers may refer back to Table 7 (presented in the Results chapter) as a reminder of the three narrative types, and eight themes, which are discussed in this chapter.

Considering Frank's (1995/2013) Narrative Types

Narratives of Restitution. Restitution stories render illness transitory; there is a focus on recovery and the "triumph of medicine" (Frank, 1995/2013, p.115). Unlike chaos narratives in which the person is a passive victim, there is a sense of agency in restitution narratives (Ezzy, 2000). Frank (1995/2013, p.77) described restitution narratives as the most common narrative type among those who have recently become ill, and the least common type among those who are chronically ill. It was therefore unsurprising that narratives of restitution did not govern the stories told by the parents in this research; even those whose children had begun struggling the most recently reported a mental illness history of at least a year, and most participants reported several years. It would also appear that restitution narratives require considerable trust in the system, accepting the medical model's promise of the ability to cure (Murray, 1999). The parents in this research described difficult relationships with healthcare professionals and dissatisfaction with NHS processes, perhaps making it less likely that they would be able to hope for the "triumph of medicine" (Frank, 1995/2013, p.115), reducing the saliency of narratives of restitution.

Furthermore, restitution narratives are "based on the assumption of a long and healthy normal life" (Whitehead, 2006) which is an assumption that many of the parents in this research no longer held, illustrated by their worries about the future, and fears that their child might not survive. Research has already found that this assumption of longevity and normality makes restitution narratives less stable for some groups such as those with HIV – Whitehead (2006) commented on the unpredictable nature of HIV and of how risk-taking behaviours can exacerbate HIV-related decline, destabilising restitution narratives. A similar argument can be made for the participants in the present research, most of whose children engaged in self-harm or other high-risk behaviours, and all within the context of a mental illness trajectory that was experienced as unknown and unpredictable. Furthermore, whether a restitution narrative can be sustained in the context of relapses in illness has already been questioned by Thomas-MacLean (2004), and the lack of restitution narratives in the present study, among parents of children with chronic mental health difficulties, would support this reservation.

Like people with HIV, people with chronic fatigue syndrome are another group who adopt restitution narratives less actively, although they were still present within narratives of those with chronic fatigue syndrome (Whitehead, 2006). The limits to the restitution narratives amongst this population were hypothesised to be connected to the nature of the illness, most notably that those with chronic fatigue syndrome face “constant reminders” of their illness in ways that participants with other (asymptomatic, intermittently symptomatic, or curative) illnesses do not, making restitution narratives more difficult to sustain (Whitehead, 2006). It was the case, strikingly, for the parents in the present research that they faced constant reminders of their child’s illness and difficulties; they described, for instance, the fear induced by regular phone calls from the wards, and the ambiguous loss of their children who, despite being absent from the family home, were constantly on their minds. This may be another reason as to why restitution narratives were not prominent in the present study.

It is interesting to consider, however, that there is a cultural preference for restitution stories (Frank, 1995/2013, p.83). Stories of restitution are thought to enable society to maintain the belief that illnesses can be healed and that suffering comes to an end (Benveniste et al., 2020). Narrators are therefore likely to anticipate that listeners want to hear stories of restitution, so this perhaps makes it more remarkable that participants in this study did not highlight these types of stories in their interviews. The interviewer had made a conscious choice to frame each interview by stating that, having worked in inpatient CAMHS some years prior, she was aware that inpatient admissions took a toll on families and was therefore interested in families’ experiences. Perhaps within this context, participants felt enabled to tell stories that were different to those that are culturally preferred. Many participants did comment that their interviews were the first occasions on which they had spoken honestly, and in depth, about their difficult experiences. It is possible that the parents told stories to friends and family that were more reminiscent of restitution narratives but were able to surrender the cultural preference for these narratives in the context of their interviews. Restitution stories have been criticised for representing the voice of medicine rather than the voice of the patients (Thomas-MacLean, 2004; Benveniste et al., 2020), so it is a strength of this research that the parents felt enabled to tell other stories. Had they spoken to a different researcher, under different circumstances, or been recorded while talking to friends and family, restitution stories would have perhaps been made more available, at the expense of other, more painful, stories.

Narratives of Quest. Quest stories “meet suffering head on; they accept illness and seek to *use* it” (Frank, 1995/2013, p.115). Frank (1995/2013) noted that most published stories of illness are quest stories. However, just as restitution narratives were not emphasised by the participants interviewed in the present research, the parents also did not narrate in a way that was indicative of Frank’s (1995/2013) quest narrative type. Perhaps, given what Frank proposes (that there is a tendency to publish quest stories in illness literature), it may be a further strength of this research that different narratives have been told.

Other authors have similarly found that quest narratives are not told by all those living with illnesses. Gray et al. (2005) found that Frank’s quest narrative could not be used to helpfully classify the experiences of black men with prostate cancer. In their small study, while the two men interviewed did share quest narratives, they were both involved in activism and other similar activities prior to their diagnoses, suggesting that they would have been able to tell stories of using their own life experiences for good prior to becoming ill. This would suggest that the quest narrative type did not emerge as a response to their illnesses and led the authors to reflect on the challenges of fitting the narratives of the two men in the study to Frank’s typology.

Similarly, only three of the twelve breast cancer narratives analysed by Thomas-MacLean (2004) were deemed to be “truly representative” of the quest narrative type. Some participants in the study were critical themselves of the existing published accounts of breast cancer (which followed quest narratives). Given the participants’ views, as well as Thomas-MacLean’s (2004) finding that quest narratives captured only a minority of participants’ narratives, Thomas-MacLean (2004) also questioned the utility of the published accounts of breast cancer, which tend to represent quest narratives.

Bally et al. (2014) spoke to parents of children with cancer. They found that although all parents told stories of restitution and chaos, not all parents told quest narratives, which the authors suggested was due to the feelings of fear, uncertainty, and loss of control experienced by the parents, as well as the fact that the children were in the early stages of treatment. In the present study, similar feelings were described by the parents, and the intensity of the worry that their children might not get better likely made it very difficult to tell narratives of quest. Perhaps, for the parents of children in inpatient CAMHS who are still in the throes of distress, it has not yet been possible to accept the suffering and make use of it (Frank, 1995/2013).

Narratives of Chaos. Unlike narratives or restitution or quest, Frank's (1995/2013) narrative type, narratives of chaos, was found to represent many of the stories told by participants in this study. In narratives of chaos, Frank (1995/2013, p.115) found that sufferers are "sucked into the undertow of illness and the disasters that attend it", and the present research has provided support for this narrative type, in which the narratives reflected the overwhelming effects of the inner chaos experienced by the narrator.

In the present study, both verbal and non-verbal cues were crucial in identifying how stories contained narratives of chaos. In these stories, parents avoided particular words or phrases by using implicit language, insinuation, or by leaving sentences unfinished; they cried, laughed unexpectedly, paused or stumbled over their own words; their stories were frequently not told in narrative order. Reflective of Frank's (1995/2013) original chaos narrative type, it seemed that parents found it difficult to tell these stories.

Within each of the narrative types in this study, a small number of themes were developed by the author, drawing either on the content of participants' stories or the way in which those stories were told. Within the chaos narrative type, three themes were developed by the author. The first of these was *critical incidents*; this theme contained the stories in which parents described moments when their child's safety or life was at risk. Just as in Frank's work, a "staccato pacing of words" (Frank, 1995/2013, p.99) was often indicative of chaos stories, particularly those in which parents described incidents of self-harm or attempted suicide. However, it was not only the content of these stories but the way they were told that made them distressing to hear, which supports the finding from Bally et al.'s (2014) interviews with parents of children with childhood cancer: chaos stories are anxiety-provoking for both the narrator and listener. Another author, Jenks (2005), who spoke to the parents of visually impaired children, found that chaos stories were often incomplete, containing brief moments of overwhelming emotion – a finding consistent with the present research. It seems that in telling a chaos story, the overwhelming emotion spills over, meaning that the narrator evokes in the listener some of the feelings of distress they experience themselves.

Parents in this research also described the insular impact of the child's suffering and inpatient admission on the family, and these stories were categorised under the second theme, *no one feels our pain.* This theme was reminiscent of Olshansky's (1962) concept of chronic sorrow, which was described by Eakes (1995) in relation to parents of adult males with schizophrenia or bipolar affective disorder. The present study suggests that the concept of chronic sorrow also applies to parents of adolescent children with mental illnesses, and it is the first study to make this link. Furthermore, it would appear that experiences of chronic sorrow and other painful emotions are exacerbated by parents' sense that others do not recognise their distress.

The parents in this research were acutely aware of the distress of their own families, and other studies have reported similar findings. For example, Thomas-MacLean (2004) noted that chaos narratives occurred most often when participants spoke of the involvement of other people in their lives. This author described one participant who narrated clearly and whose story "flowed" through restitution and quest narrative types until she began describing the impact of her illness on her family, marking the beginning of a chaos narrative. This change in narrative type can be understood to be indicative of her distress at the impact that her illness has had on her family. In the present research, participants appeared attuned to the impact of their children's illnesses on the whole family, and many of them were exceedingly concerned about what the implications of this might be. By developing this concept into one of three themes within the chaos narrative, the present study has gone beyond that of previous research; the sensitivity and acuteness of participants' awareness of their families' suffering is captured, as is their intense concern that the pain of the family unit is not witnessed by others. These feelings of painful isolation and loneliness have not been connected to chaos narratives in previous literature.

Lastly, parents' worries about the future were included in the theme *what if s/he doesn't get better?* Parents' sense that control had been taken from them was indicative of the chaos narrative type, and the loss of control made it difficult for parents to imagine a future in which their child did not struggle. Quite unlike restitution stories, in which the narrator describes the triumph of medicine over illness, the trajectory of their children's illnesses, which appeared non-linear and unpredictable, perhaps contributed to parents' difficulties in imagining a future in which their child were well. Furthermore, the difficult emotional responses the children had to their admission, as well as to the psychological and pharmacological treatment they were offered, reduced parents' confidence in their child's healthcare and exacerbated their doubts about the future. This echoes Bally et al.'s (2014) finding that parents' chaos narratives were revealed at times of diagnosis, changes in treatment, and in response to their child's emotional and physical reactions to treatment. In Bally et al.'s (2014) research, the parents were similarly unable to imagine their child's future; the authors noted that uncertainty and doubt were described by their participants in the same way that parents in the present study both implicitly and explicitly described their fears about the future.

Proposing New Narrative Types

A small number of researchers have adopted Frank's (1995/2013) suggestion to use his original narrative types as listening devices and to subsequently propose new narrative types, as the present study has done. Existing research in which parents of ill children have been interviewed is particularly relevant to the present study. Jenks (2005) studied the narratives of parents who have blind children. Like some others, she found that Frank's (1995/2013) three types were present, but she reflected on the cultural preference for restitution stories, and the publication bias towards quest stories, which makes these appear more prominent than they may otherwise be. Reflecting on her own experience as a mother of a blind child, she proposed a fourth narrative type: narratives of explanation. She noted that these narratives of explanation will differ depending on the narrator's audience and context. It is arguable that narratives, more generally, will differ in the face of changing audiences and contexts. This is suggested by the present research.

Another study which found that Frank's (1995/2013) three narrative types did not sufficiently capture illness experiences was by Benveniste et al. (2020), who interviewed parents of children with end-stage renal disease. The authors conceptualised a new narrative frame in the form of a circular model which they called the Sisyphean narrative. This moved away from Frank's types, which they deemed "linear". Another author, Ezzy (2000), has similarly noted that Frank's narrative types have a temporal orientation. Consideration of the somewhat linear and temporally bound nature of Frank's narrative types may offer an explanation as to why restitution and quest narratives did not underscore the narratives of the participants in the present study. In order to tell a story in which health triumphs over illness, one requires the ability to be future-oriented and to minimise the experience of illness (Ezzy 2000). The parents of children in inpatient CAMHS worried about the future and, at the time of their interviews, found it challenging to imagine a future in which their children do not struggle. The distress of the children was not minimised and was, instead, at the forefront of the parents' minds. As suggested by Ezzy (2000), these factors perhaps disabled narratives of restitution.

Frank's narrative types have nonetheless been helpful for many researchers studying illness experiences, and it was an interesting, and initially surprising result, to discover that while his three narrative types could be helpfully used as listening devices, they did not feature in this research in the way that Frank has proposed. As opposed to narratives of restitution and quest, the new narrative types proposed by the author, conflict and distance, were a better fit for the parents' stories, in conjunction with Frank's original chaos narrative type.

Narratives of Conflict. Narratives of conflict reflected the inter- and intra-personal conflict experienced by parents. Parents' frustrations with the wards, the procedures, and the staff were captured by the theme *feeling trapped in an NHS system*. These experiences of frustration and stuckness have been described by parents in comparable studies; in the meta-ethnographic synthesis which preceded this research, every study commented on participants' descriptions of the help-seeking processes which included negotiation with services and staff and often yielded frustration and disappointment. For parents, this seems to be a particularly important topic; in the present study, parents often returned to this topic even when it was not related to the question they had been asked. Perhaps this is due to the nature of the sample; the participants may have volunteered to take part because they wanted to voice their frustrations, and the NHS system was one significant area of frustration. As in any self-selected sample, the participants may reflect a particular type of parent who has had a particular set of experiences. Alternatively, the interviewer-interviewee relationship may have been important in producing these narratives. The parents implied that they did not have many opportunities to voice their frustrations directly to those involved in their child's care, and many of the parents commented that when they did have an opportunity to do so they did not feel that their concerns were taken seriously or that their opinions as parents were valued. The interviewer perhaps represented an NHS professional to whom the parents could voice their frustrations, in the absence of other professionals. Perhaps it is also more manageable for parents to direct their frustrations towards the NHS system, as opposed to their children, their families, or themselves.

The theme *one of us has to be the stronger one* captured the differences between partners as well as the parents' perceived differences between themselves and the parents of healthy children. Consistent with the tendency for women to be the primary caregivers in the home, mothers took on the majority of the caregiving role. This unequal division of caregiving involvement was described by both mothers and fathers, supporting the findings of Johansson's (2012) research in which fathers acknowledged the role mothers play in assuming the majority of the caregiving "burden". This also provides support for related research into caregiving in the context of adult depression, in which women describe "constant vigilance" in their caregiving role (Oute & Huniche, 2017). Nonetheless, fathers in the present study were far from being a "peripheral parent" (Herbert & Carpenter, 1994); they involved themselves in their child's care and were significantly affected by their child's difficulties. One father was frustrated by what he perceived as the ward's failure to sufficiently include him in his child's care, wanting to be more involved, and the fathers' narratives taken together indicated significant suffering and intense commitment to their child, supporting a finding from earlier research in which fathers felt more committed to their child as a result of the child's disability (Carpenter & Towers, 2008).

None of the parents suggested that the share of responsibility had changed, rather, the differences in caregiving responsibilities appeared to reflect the way in which caregiving was shared between partners prior to their child's difficulties. Several parents noted that their child had always had a closer relationship with their mother than with their father. For many of the families, the fathers provided practical support, while mothers appeared to assume the role of advocate and provided the majority of the emotional support to the child. The importance of a supportive couple relationship in the context of parenting a child with a mental illness has been noted in previous research, such as in Gok and Duyan's (2020) study, in which mothers assumed almost all caregiving responsibilities but felt empowered by the support of their partners. However, in the present study, while parents felt that they and their partners were working towards the same goal, some noted that the relationship had nonetheless become strained, and they had a sense that they were alone despite working towards the same goal as their partner. This emerged, in part, through differences in coping styles, with one parent typically becoming emotional and expressing their distress while the other parent took on the problem-solving role and expressed less emotion; these differences created some conflict within relationships, and parents were left feeling as though they were struggling on their own. Within a couple, parents typically considered one partner to be the "stronger" one, although there was no clear gender divide. Parents wanted to become "normal" parents again, contrasting their experiences to those of couples whose children were not experiencing mental health difficulties. The significant stress and turbulence caused by the admission placed a strain on the couple relationship.

Narratives of Distance. Narratives of distance comprised parents' stories of physical and psychological distance, as well as stories in which parents appeared emotionally distanced from their experiences.

The first theme, *admission provides respite but it doesn't last*, connects the initial experiences of relief and respite at the point of admission with later experiences of distress as the admission progresses and relief wanes. Experiences of respite, relief and hopefulness have been described by parents of children with mental illnesses at the point of commencing treatment (Brown, 2018), but the present research extends these findings by noting that stress returns after a brief period of respite. The admission initially provides some distance from the intensely stressful circumstances that preceded the admission, which affords parents some relief and hope. However, this does not last; the children continue to struggle, and the parents realise that there is a long road ahead. The parents described how their children's difficulties impacted every area of their lives; many parents were unable to work, their social lives and hobbies were reduced or placed on hold entirely, and their physical and psychological health were negatively affected.

Distance narratives also contained the narratives of parents who appeared to have emotional distance from their experiences. When the content of parents' stories seemed in contrast to the emotions they were describing or displaying, this was suggestive of some emotional distance from their experiences. Participants who demonstrated contrasting emotional responses (such as laughter) while discussing distressing events appeared to be finding distance from their emotions; some parents were conscious of this and openly acknowledged it, while others did not comment on the incongruity between their behaviour and words. The use of emotional distance could be considered as a way of coping with difficult experiences; the majority of these parents had no option other than to continue caring for their families, and many were still working, so coping in this way perhaps enables these parents to carry on despite highly distressing events. Future research could explore this further.

The results provided support for the application of the theory of ambiguous loss to parents of children in inpatient CAMHS, and *ambiguous loss* therefore formed the second theme within narratives of distance. Ambiguous loss was experienced in a number of different ways by parents. For some, the experience of ambiguous loss was so intense that it was as though their child had died. Parents described how despite physical absence (an empty bedroom or empty seat at the dinner table), their child was always on their mind. Parents who were unable to spend any time with their child were highly distressed by this distance, and either sought ways to feel psychologically closer to their child or, contrastingly, found that they were so overwhelmed by the child's constant presence on their mind that they sought ways to reduce this. This preoccupation with thoughts about their child supports Boss' (2002) conceptualisation of the first type of ambiguous loss, in which a person is physically absent but experienced, psychologically, as present. Some parents also commented on subtle changes they had noticed which meant that, despite being able to spend time with their child, they experienced psychological loss. Examples included loss of their identity as the child's parent, a sense that they had lost their voice, or an inability to recognise their child in the way that they had before. This experience of physical presence but psychological loss provides support for the second type of ambiguous loss, which Boss (2011) applied in the context of dementia. The results from this study therefore suggest that the theory of ambiguous loss can be helpfully applied to the parents of children in inpatient CAMHS, to aid an understanding of the parents' difficult emotional experiences.

The third theme, *the passage of time*, includes stories of hope for the future. This is in stark contrast to chaos narratives, in which parents struggled to imagine a future in which their child was well. The difference for the parents who told hopeful stories is that the passage of time had provided them with some distance from many of the distressing experiences they had lived through, giving them a sense that the worst was over and that their child was getting better. Other circumstances facilitated the telling of these stories, including positive, supportive relationships with staff members, a strong couple relationship, and improvement in their child's mental health. Parents who did not have these experiences at the time of their interviews appeared to find it challenging to think about the passage of time or reflect upon their experiences, and they told far fewer stories of hope for the future. These types of narratives, therefore, seem highly dependent on the narrator's current experience, as well as their psychological and temporal distance from distressing events. It is possible that many of the parents in this study would tell stories of hope for the future if interviewed at a later point in their child's recovery. It is unsurprising that the parents whose narratives were most dominated by chaos stories told the fewest stories of the passage of time.

Chaos, Conflict and Distance

This research has illustrated, through the stories told by parents, that parents are profoundly affected by their children's mental illnesses and inpatient admissions. Taken together, the three narrative types, chaos, conflict, and distance, could be considered to reflect the different responses parents have to highly distressing situations and uncontained feelings.

Most parents' interviews contained all three narrative types. However, at any one point in an interview, it was possible to identify a singular narrative type as guiding a parent's story; this would change as and when different stories were told. As illness is biographically disruptive, individuals are forced to change the stories they tell about their lives. Milliken (2001) called this a process of "redefining parental identity", and Karp (1994) described the turning points of a "caregiving career" which are characterised by different emotions. Therefore, these narrative types, rather than remaining stable over time, should be understood to be capturing parents' inner worlds at a specific moment in time. The time during which a child is receiving treatment in inpatient CAMHS appears to be a particularly distressing and destabilising time for parents, and this is reflected by the three narrative types. Had the parents been interviewed at a different point during their child's illness, such as the time at which they first noticed changes in their child, it is likely that different stories would have been shared and different narrative types would have been developed. It would be reasonable to think that parents' narratives manifest differently over time.

Individuals do not remain passive in the face of illness (Murray, 1999) and the three narrative types could be conceptualised as the parents' attempts to make sense of their experiences and emotions in order to move forward. The parents in this study experienced an array of difficult emotions; it was clear that while they did not experience their children's illnesses, the illnesses impinged upon the parents' emotional worlds. Jacoby et al. (2021) suggested that children's illnesses are "forced" upon the physical and emotional worlds of parents, and the authors used the term "the ill unit" to describe the parent and child's shared experience of the child's illness. The present study provides support for this concept and offers the three narrative types as a way of understanding how one group of parents, those of children in inpatient CAMHS, tell the stories of their lives when faced with such significant biographical disruption.

Critical Reflections on the Research Process and Role of the Researcher

Researchers conducting narrative research have been warned against the temptation to treat stories as though they are reflections of reality (Leavy, 2014, p.203) or to indulge in the “frequent ignorance of the interpersonal context in psychological research” (Murray, 1999, p.55). Maintaining a critical realist position on whether, and the extent to which, research findings can represent reality meant that the results from this study are considered socially, culturally, and contextually situated, with the researcher engaged in a process of co-constructing language and meaning with each participant. Each participant would have narrated his/her story differently on another day, in another context, and to another audience; narrators have “options and alternatives” available to them (Carr, 1986, as cited in Leavy, 2014). In other words, a story is not the same as an experience (Leavy, 2014, p.202). Reflexivity on the part of the researcher is therefore needed in order to consider the role s/he plays in influencing how stories are told and what types of stories are told. Reflexivity also encourages the researcher to consider how his/her own experiences will shape how s/he interprets narrators’ stories, and how this influences which stories s/he chooses over others. As such, the remainder of this section on critical reflections uses the first-person perspective. Some of the critical reflections made over the course of the research are described, focusing particularly on the research process and the role of the researcher in relation to the medical model and to the method of analysis. This section will therefore be “less anonymous and more personal” (Leavy, 2014, p.206).

Impact of the Medical Model

I have considered whether one can really assert to be working within a critical realist ontology while also using the language of diagnoses and disorders which is so aligned with the medical model of disease and relies on an uncritical and tacit acceptance of the use of a diagnostic manual to produce a label of mental illness. However, as outlined in the Introduction chapter, I have reflected on how the use of a shared language can be helpful and I have acknowledged that a diagnosis of a mental illness is a pre-requisite for admission into a CAMHS ward. It has been noted that the parent-child dyad (the “ill unit”) involves the healthcare system as a “third party” (Jacoby et al., 2021), and in a study so connected to a healthcare system (inpatient CAMHS), this cannot be ignored. It is nonetheless possible that the medical model, with its emphasis on diagnosis and treatment, makes it more challenging for families to think in the way that would be encouraged by a family systems approach. For example, I was surprised to discover, during the interviews, how often parents would speak about their child's difficulties (with great concern) when they were asked to speak about their own psychological experiences. Even when asked direct questions about how their child's admission had impacted them as parents, parents would often revert to describing their child's distress. Perhaps the labelling of the child with a diagnosis encourages this focus. A family systems approach would instead consider the distress within the whole family, and the results of this thesis are certainly consistent with the idea that the whole family suffers, and is destabilised, in the context of the child's distress.

Alternatively, parents' tendencies to speak about their children's difficulties perhaps connects to the self-sacrifice that is required when parenting a child with additional needs. The parents in this study placed their children's needs above their own, sacrificing hobbies, friends, and work, in order to be able to continue caring for their children. This commitment to caregiving was also found in the studies reviewed in the meta-ethnographic synthesis presented earlier in this thesis, in which parents viewed caregiving as "an unavoidable role". Furthermore, the conclusions from a study involving the parents of children with end-stage renal disease (Jacoby et al., 2021) offer a helpful way of understanding this phenomenon. The authors noted that when a parent becomes responsible for a child's survival, not dissimilar to the role that the parent assumed when the child was an infant, the parent will "become fully invested in the child and inhibit his or her own subjective needs" (Jacoby et al., 2021). Perhaps continually placing their children's needs above their own affects what stories are most readily available for parents to tell. It has been noted that mothers, in particular, place value on caring for others, while they consider caring for themselves to be selfish (Scheyett, 1990). It is possible that it was an unusual experience for these parents to be asked to think about their own emotional experiences and prioritise their own feelings above those of their children for the duration of their interviews.

Method of Analysis

Early on in the research process I experienced a dilemma about the analytical method that I would use. During the design of the research, I initially considered thematic analysis (Braun & Clarke, 2006), noting that I could use this analytical method within a critical realist ontological position, that reflexivity was encouraged, and that there was a clear analytical framework to follow. However, I was concerned that analysing interviews systematically and line-by-line, in the way that is typical of thematic analysis, would detract from the experiences of the stories in their entireties, that the tone of the interviews would be lost, and that this would result in stories that would become “devoid of spirit” (Frank, 2010). I did not want to reduce the data to a set of themes or categories that did not capture the dramatic engagement (Gergen & Gergen, 1986) or emotional flavour (Murray, 2015) of the interviews. I felt that the whole was more than the sum of its parts and wanted the reader to be able to “experience the experience” of the narrator (Ellis & Bochner, 1992, p.98).

I decided to begin interviewing participants, and to use the early interviews to help me to decide on an analytical method. I made use of my reflexive log (Appendix H) to note my thoughts after each interview, and observed that I felt strongly, after the first interview, that an approach like thematic analysis would not do justice to the participants’ stories. As I continued interviewing, I found that I felt invested in each participant’s story. Rather than distancing myself from the participants and their stories for the sake of some level of objectivity or scientific rigour, I developed a “caring relationship” with each one (Bochner, 2010; 2017). I was listening with interest to their stories, going beyond the semantic content, and beginning to connect with their experiences emotionally, perhaps in the way described by Bochner (2017) as engaging in research with both head and heart.

In addition to the reasons for using narrative analysis outlined in the Methods chapter, the decision to use narrative analysis was reinforced by the reflections that I made during, and in between, interviews. I acknowledged that the engagement with stories that is enabled through a narrative analysis would mean that I would be more likely to “recognise why the story matters deeply to the person telling it” (Frank, 2010). I considered how the write-up of the analysis would also allow me to present stories that I thought would “activate subjectivity and compel emotional responses from readers” (Leavy, 2014, p.206). I therefore resisted abstraction, developed relationships with the participants’ stories, and paid attention to my own role in the research process, acknowledging that the stories were made rather than found (Bochner, 2017).

I was also aware that published accounts of illness, including mental illness, tend to reflect recovery or reveal the ways in which people retrospectively find meaning from illness, as observed by Frank (1995/2013) in his description of quest narratives. While these may provide hope and optimism for individuals and families in the throes of distress, they do little to validate experiences of distress, nor do they provide any insight into those experiences. Furthermore, it has been noted that even when brief chaos narratives are published, they are found within essays which nonetheless contain the message that, with time, parents will feel better (Jenks, 2005). An important guiding principle of this research was that the presentation of the analysis would provide readers with a sense of what it is like to live through the experiences described by the participants in this research (Brochner, 2017), rather than over-emphasising culturally preferred narratives of hope, recovery, and wellness. It is not that the parents interviewed in this research will not feel better with time, but that the stories they chose to tell in their interviews instead reflected the chaos, conflict, and distance they were experiencing at this time in their lives. I would agree with Bally et al.'s (2014) impression that the telling of chaos stories is both distressing and healing for the narrator; to have focused the analysis instead on hope or optimism would have meant a dishonest representation of their stories.

Methodological Limitations of the Research

The methodological limitations of the research will now be explored, and the impact these may have had on the results of the research will be considered.

While there was some diversity within the sample, particularly with regards to age of the participants, the children's diagnoses, and the duration of the children's mental health difficulties, a larger and more diverse sample may have provided opportunities for consideration of differences amongst the participants. The sample was mostly White British, with only three participants from other ethnic backgrounds. However, consultation of the 2021 census data (ONS, 2022) indicates that this is representative of four of the five local authority districts within England from which participants were recruited. The fifth ward was based in an area in which White British was not the dominant ethnic group, but only one participant volunteered to participate from this ward. As such, any differences in experiences that may be related to participant ethnicity were not explored in this research.

Furthermore, while the results of this study are likely to be meaningful and of use to countries other than England, some aspects of the results may be particular to the experience of parenting a child in an inpatient CAMHS ward in England. For example, the stigma attached to a diagnosis of a mental illness differs across countries, with individuals in Eastern countries reporting more stigma than those in Western countries (Krendl & Pescosolido, 2020). Among other things, mental health stigma is a barrier to help-seeking (Clement et al., 2015) so would have an impact on which families access services, and thus are able to participate in research, meaning that any future research conducted in other countries may generate different conclusions. Additionally, healthcare, including inpatient CAMH services, is free at the point of access in England; parents in countries that do not have a publicly funded health service are likely to face the added pressure of having to fund their child's admission, and may have different expectations and experiences of healthcare. The systematic review presented in an earlier chapter included studies from a number of different countries; treatment settings differed across countries, as did parents' experiences, although it was not possible to make conclusions about what caused these differences. The present study is the first to explore the subjective experiences of parents of children in inpatient CAMHS and has focused on England; researchers may wish to draw on the results of this study in their own investigations into parental experiences in other countries.

All participants were in heterosexual relationships or had been in heterosexual relationships prior to separation, so experiences of parents in same-sex relationships were not considered in this research. Furthermore, at the time of their interviews, the majority of participants were in a relationship and co-parenting their child with their partner. Only three of the fifteen participants were single parents (mothers). Specific differences relating to relationship status were not considered. This is a limitation of the research, given that research suggests that single parents (mothers) experience higher levels of stress, and that having a child with a disability is a specific risk factor for increased levels of stress (Sartor et al., 2023). Further research could seek to ascertain whether single parents of children in inpatient CAMHS are at higher risk of stress and stress-related consequences and thus are in need of additional support.

Two-thirds of the sample were mothers. While this is not dissimilar to existing research into parental experiences of childhood mental illness, in which samples generally have a significant female majority (e.g. Thomson et al., 2014; Stapley et al., 2016; Bai et al., 2020; Sarrio-Colasa et al., 2022), involving more fathers in this research may have made it possible to consider more purposefully whether mothers and fathers have different experiences. Discourse around caregiving is highly gendered (Oute & Huniche, 2017), so a critical consideration of gender could be made a focal point of future research.

Participants had a range of different experiences in relation to their child, and it is possible that individual characteristics of the participants impacted the results. The children had a variety of diagnoses, and it is likely that different diagnoses impact parents in different ways. For instance, in the systematic review conducted prior to this research, there appeared to be some differences across diagnoses, with a diagnosis of schizophrenia, in particular, being received negatively and inciting concern in parents. However, relationships between child diagnosis and parental experience could not be determined in either the systematic review or present research. In the present research, there were also differences in the duration of the children’s mental health difficulties as well as the lengths of time they had been on the wards. It is possible that a longer duration of difficulties leads to increased stress or burn-out in parents, or, contrastingly, it may mean that parents have developed coping strategies and support networks that enable them to cope with their experiences. This also could not be determined by the present research. Next, some parents had experiences of parenting their child through more than one inpatient CAMHS admission; for one parent, this enabled them to pay attention to the positive differences the family experienced during the second admission when compared to the first. Yet, for other parents, multiple admissions led to feelings of hopelessness, so the relationship between illness duration and/or admission duration is unclear. Lastly, all children were of similar, late teenage, age. Although this is representative of the majority of children in inpatient CAMHS (NHS Digital, 2021), as parents of younger children did not participate in the research it is not possible to say whether the age of the child affects the parent’s experience. To summarise, it was not possible to determine whether individual characteristics of the parents and/or their children had an impact on their experiences, nor was this the aim of the present study. Future research may attempt to look for relationships between child characteristics and parental experiences.

The decision to allow participants to choose whether to attend an interview on their own or with their partner represented both a methodological and ethical choice: it was anticipated that this might facilitate recruitment by allowing participants to choose the option that best suited them, but it also allowed participants to decide whether a partner’s support in an interview would be helpful. However, it is possible that the four participants (two couples) who attended interviews with their partners may have discussed different topics if they had attended interviews on their own; the presence of a partner may have been supportive but may have also prevented individuals from bringing up sensitive topics or speaking candidly.

During the process of transcribing the interviews, non-verbal cues were noted and subsequently used to inform the analysis. Qualitative researchers have noted that the inclusion of non-verbal communication enhances both the quality and quantity of the data, and that the clear documentation of non-verbal data enhances the validity and credibility of the results (Begley, 1996). However, while the inclusion of non-verbal cues contributed to the richness of the data, the analysis of these cues is noted here as a possible limitation of the research due to the subjectivity involved in this process. It is unlikely that all non-verbal cues were transcribed, meaning that some will have been missed from the analysis. It is also possible that these cues may have been interpreted differently by a different researcher. In future research, this could be addressed by having multiple researchers watch the videos and code the non-verbal cues, allowing for intercoder reliability to be ascertained, as described by O'Connor and Joffe (2020). The benefits of transcribing and analysing non-verbal cues were considered to outweigh the possible costs, but, as with all qualitative analysis, bias and subjectivity on the part of the researcher cannot be eliminated.

A final limitation to mention here is the lack of patient and public involvement (PPI) in the research. With regards to the design and delivery of the research, the involvement of parents and professionals with current or past relationships to comparable inpatient CAMH services may have helped to ensure that the research was considered relevant and important to those with a personal or professional connection to the topic. Among other things, PPI may have positively impacted how participants were recruited, the questions asked in interviews, and the way in which data was analysed and conclusions were drawn. However, PPI beyond token involvement (Jennings et al., 2018) was felt to be beyond the scope of this project, given the resources available to a Trainee Clinical Psychologist conducting research on a Doctorate in Clinical Psychology programme. More time, funding, or the provision of research assistants to support the research may have made PPI possible.

Suggestions for Future Research

Areas for future research can be considered in relation to the critical reflections and methodological limitations of this research, as discussed above.

An issue which persists in research in this area is that fewer fathers than mothers are recruited and interviewed in studies. It has been noted that, generally, mothers take on the role of primary caregiver and are also particularly vulnerable to criticism of their parenting skills (Lawrence, 2011). However, further research into paternal experiences in the context of children with mental illnesses would enable better understanding of the experiences of fathers and allow for comparisons to be made between mothers' and fathers' experiences. It would also be interesting for future research to study the impact of a child's mental illness and/or admission to inpatient CAMHS on siblings; the present research would suggest that entire families are affected and this could be made a focus of future research.

A further consideration for future research would be to investigate how parental narratives differ when parents are interviewed earlier or later on in the process of negotiating their child's inpatient admission. Perhaps transition points, such as the time of admission or discharge, could be concentrated on in future research. A longitudinal study, interviewing family members at different time points, would help to uncover how people revise their narratives in order to make sense of their lives (Ezzy, 2000). Understanding the experiences of parents at specific timepoints would be helpful in tailoring support to families at these times of change.

The interviews conducted in this research were relatively long (only one interview was shorter than 60 minutes in duration) and this research has therefore produced a useful amount of data. Individual transcripts could be re-analysed to gain a more detailed understanding of an individual's account of their experience. The method used by Poindexter (2003), who chose one interview from her existing dataset to re-transcribe using Gee's (1986, 1991) poetic structural approach, would be one way of approaching this in future work. It would allow for a closer, more meticulous examination of word choice, context, and meaning, and would offer the analyst the opportunity to attend more closely to language and ambiguities (Poindexter, 2003). Interviews for re-transcription and re-analysis could be selected based on criteria to address a specific research question, perhaps to look more closely at a father's experience, the experience of a parent from a non-White British background, or to examine how a couple interviewed together negotiate the telling of their stories.

Finally, researchers should be encouraged to use the narrative types proposed in this thesis (chaos, conflict, and distance) as listening devices (Frank, 1995/2013) in their own research. This may include research involving parents of children with physical health problems or disabilities, or parents caring for adult children with mental health difficulties, to see whether the narrative types are also found to be present in these stories. This might extend the implications of this research to wider caregiving contexts.

Implications of the Research

The contributions offered by this research to narrative theory on illness have already been explored. This section discusses the clinical implications of the research.

This thesis has emphasised the importance of telling, and publishing, stories that are outside of the dominant narratives. Unlike narratives of restitution and quest, narratives of chaos have not been prioritised (Frank, 1995/2013), and stories of conflict and distance have not been described before. These stories need to be told and to be heard; when a person's story is denied, they cannot be cared for (Frank, 1995/2013, p.115). This is an important message for clinicians working in inpatient CAMHS.

Just as Frank (1995/2013) proposed that his narrative types can be used as listening devices, the narrative types proposed in this thesis could be used as listening devices by clinicians working with parents like those involved in this research. The narrative types of chaos, conflict, and distance offer a new way of understanding and conceptualising parents' experiences. The narrative types offer clinicians a way to make sense of stories, so that experiences can be understood and valued in a way that may improve the clinical care provided by staff members (Thomas-MacLean, 2004).

This research has demonstrated, for the first time, the immense strain that is placed on the parents of children who receive treatment in inpatient CAMHS. This would suggest that there is significant need for parents to receive support in order to help them cope with their experiences. Given that the majority of children in inpatient CAMHS, upon discharge from the wards, will return to the care of their parents, parents need to be supported so that families have the best chance of successfully managing this transition. This is particularly important when considering that the subjective burden experienced by family caregivers may have serious health implications for both the caregiver and the person with the diagnosis (Oute & Huniche, 2017).

Clinicians working in inpatient CAMHS may consider increasing parental involvement, offering parent-to-parent support, or providing psychological therapy to parents; these are explored below.

Increasing Parental Involvement

Many parents did not feel sufficiently informed about decisions regarding their child's care. Some parents were frustrated when they did not receive updates from ward round, when they received conflicting information from different clinicians, or when they were not phoned after significant events on the ward.

Parents should be kept informed about their child's progress, wellbeing, and activities on the ward. This will need to be considered on an individual basis – while some parents will want to be updated after every incident on the ward, other parents will prefer not to be phoned at night, for instance. Some parents may want a daily update, while others may visit their child regularly and not require updates by phonecall. In the interviews, some parents described finding out that their child had been taken to general hospital a day or more after the event, suggesting that clinicians forget to update parents, or may not be aware of parents' preferences regarding updates about their child. Parents should be asked about their preferences at admission, and this should be reviewed regularly. Parents' preferences should be noted and stored on the child's electronic patient record. When a mistake is made, clinicians should acknowledge this, apologise to families, and take steps to ensure that the same mistake does not happen again in the future.

It was also common for parents to describe anxiety in relation to knowing how to help their child, either when their child was on home leave or with regards to thinking about their child's future discharge from the ward. Parents should be enabled to develop the relevant skills in order to feel better equipped to support their child. Research has found that involving parents in delivering their child's therapy has positive implications with regards to parental empowerment (Allard et al., 2022) and parental well-being and mental health (Lawrence et al., 2021). This suggests that parents of children in inpatient CAMHS would benefit from being involved in their child's therapy. This will not be appropriate for all families, and will depend on the nature of the child's therapy and would require the child to consent to parental involvement in therapy. If may be more appropriate for some parents to be supported in other ways, such as through parent-to-parent support.

Parent-to-Parent Support

Many parents described the difficulties of speaking to friends and family about their experiences and emotions. This was often connected to a sense that people would not feel comfortable listening, or would not understand – many described a belief that only other parents of children in inpatient wards would understand them. This led parents to feel that they could not speak candidly with friends, or to reduce contact with their friends; this was compounded by the demands of visiting their child, supervising their child on home leave, and continuing to look after other family members and engage in their usual daily activities.

A minority of parents had attended parent support groups offered by the wards. They spoke highly of these, describing how helpful it had been to speak to other parents who understood them as a result of their shared experience. Some parents had sought out further ways to connect with parents in similar situations, describing Whatsapp groups or Facebook pages. Other parents were aware that support groups were offered by their child's ward, but were unable to attend due to living a significant distance away from the ward, or needing to balance other demands (employment, childcare, etc.).

This suggests that parent-to-parent support may be beneficial for some parents, although not all. Some existing research has noted the benefits of parent-to-parent support.

In the context of children with disabilities, parent-to-parent support has been found to reduce parental stress and increase feelings of belonging (e.g. Kerr & McIntosh, 2000; Law et al., 2002). Similarly, a pre-post study by Martin et al. (2019) found that a peer-delivered intervention by and for parents of children with developmental disorders (such as ASD and ADHD) significantly lowered parental anxiety and depression, and enhanced their well-being, as well as feelings of gratitude and hope.

The parents of children in inpatient CAMHS should be offered parent-to-parent support. This could be in the form of a regular (i.e. fortnightly) support group. This could be facilitated by a CAMHS clinician, or by an external clinician. For those parents who are not local to the wards, or cannot travel to the ward for other reasons, some support groups could be offered online.

It is unlikely that peer support groups will be appropriate or suitable for all parents. It is also possible that some parents will require a more tailored intervention. Psychological therapy could be offered to these parents.

Psychological Therapy

Tailored, psychological support could be offered to parents in order to help them to deal with their own difficult experiences, which could take the form of individual, couple or family therapy. In addition to parent support groups, psychological therapy would provide parents with opportunities to tell their stories in supportive environments. This could take the form of family therapy or individual therapy. The present study would suggest that systemic family therapy or individual narrative therapy may be helpful for parents, given their respective emphases on considering distress within a family system and on working with the stories people tell about their lives. It is possible that if parents are better supported, particularly by having access to psychological therapy themselves, they will feel more equipped to deal with their challenging family circumstances, meaning that they will be in a better position to support their child when s/he is discharged from the ward. As such, this could have positive effects on both parent and child wellbeing.

The possibilities discussed here would need to be explored in future research. Future research could evaluate existing parent-to-parent support groups, explore current parental involvement in CAMHS wards, and pilot the use of psychological therapy for parents of children in inpatient CAMHS.

Conclusion

This is the first study to explore the experiences of subjective burden in parents who have a child who is receiving treatment in an inpatient child and adolescent mental health service. Parents' stories contained three narrative types: narratives of chaos, narratives of conflict, and narratives of distance. These narrative types can be considered to represent the different responses these parents had to highly distressing situations and uncontained feelings, and their attempts to make sense of their experiences and emotions in order to move forward.

This research offers contributions to narrative theory, adds to the literature on family caregiving, and has implications for clinical practice. This research has shown, for the first time, the significant, subjective, impact on parents when a child receives treatment in inpatient CAMHS. Stories have a unique capacity to connect people (Frank, 2010), and this research may encourage readers to reflect on how parents are affected by a child's mental illness and admission to inpatient CAMHS. The new narrative types could be used as listening devices by clinicians working with parents of children in inpatient CAMHS to better understand parents' experiences and to tailor therapeutic interventions to support them. Future research may consider how parents' narratives manifest differently over time as they negotiate their child's mental health difficulties and inpatient treatment.

References

Ahlström, B. H., Skärsäter, I., & Danielson, E. (2009). Living with major depression: experiences from families' perspectives. *Scandinavian Journal of Caring Sciences*, *23*(2), 309-316.

Akgül Gök, F., & Duyan, V. (2020). 'I wanted my child dead'–Physical, social, cognitive, emotional and spiritual life stories of Turkish parents who give care to their children with schizophrenia: A qualitative analysis based on empowerment approach. *International Journal of Social Psychiatry*, *66*(3), 249-258.

Alase, A. (2017). The Interpretative Phenomenological Analysis (IPA): A Guide to a Good Qualitative Research Approach. *International Journal of Education and Literacy Studies*, *5*(2), 9-19.

Allard, C., Thirlwall, K., Cooper, P., Brown, A., O'Brien, D., & Creswell, C. (2022). Parents' perspectives on guided parent-delivered cognitive behavioral therapy for childhood anxiety disorders: A qualitative study. *Journal of Emotional and Behavioral Disorders*, *30*(3), 235-244.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.).*

Andersen, P. H., & Kragh, H. (2010). Sense and sensibility: Two approaches for using existing theory in theory-building qualitative research. *Industrial marketing management*, *39*(1), 49-55.

Armitage, S., Parkinson, M., Halligan, S., & Reynolds, S. (2020). Mothers' experiences of having an adolescent child with depression: An interpretative phenomenological analysis. *Journal of Child and Family Studies*, *29*, 1617-1629.

AYPH (2021) Child and adolescent mental health services (CAMHS). *Association for Young People's Health.* https://ayph-youthhealthdata.org.uk/key-data/use-of-health-services/child-and-adolescent-mental-health-services-camhs/

Bai, X. L., Luo, Z. C., Wang, A., Guan, Z. Y., Zhong, Z. Y., Sun, M., & Tang, S. Y. (2020). Challenge of parents caring for children or adolescents with early-stage schizophrenia in China: A qualitative study. *Perspectives in Psychiatric Care*, *56*(4), 777-784.

Bally, J. M., Holtslander, L., Duggleby, W., Wright, K., Thomas, R., Spurr, S., & Mpofu, C. (2014). Understanding parental experiences through their narratives of restitution, chaos, and quest: improving care for families experiencing childhood cancer. *Journal of Family Nursing*, *20*(3), 287-312.

Barker, C., Pistrang, N., & Elliott, R. (2002). *Research methods in clinical psychology: An introduction for students and practitioners*. John Wiley & Sons.

Beck, J. S., & Beck, A. T. (2011). *Cognitive behavior therapy: Basics and beyond.* The Guildford Press.

Begley, C. M. (1996). Triangulation of communication skills in qualitative research instruments. *Journal of advanced nursing*, *24*(4), 688-693.

Benveniste, S., Goldzweig, G., & Jacoby, R. (2020). Illness Narratives Through the Eyes of Parents of Children With End-Stage Renal Disease. *Qualitative Health Research*, *30*(12), 1798-1806.

Bergin, M., Wells, J. S., & Owen, S. (2008). Critical realism: a philosophical framework for the study of gender and mental health. *Nursing Philosophy*, *9*(3), 169-179.

Bochner, A. P. (2010). Resisting the mystification of narrative inquiry: Unmasking the real conflict between story analysts and storytellers. *Sociology of Health & Illness*, *32*(4), 662-665.

Bochner, A. P. (2017). Heart of the matter: A mini-manifesto for autoethnography. *International Review of Qualitative Research*, *10*(1), 67-80.

Boss, P. (2002). Ambiguous loss in families of the missing. *The Lancet*, *360*, s39-s40.

Boss, P. (2011). *Loving someone who has dementia: How to find hope while coping with stress and grief*. John Wiley & Sons.

Boss, P. (2018). Spiritually Coping with the Bind between Trauma and Ambiguous Loss as Experienced by Foster Children. *Story, Formation, and Culture: From Theory to Practice in Ministry with Children*, 159.

Bowen, M. (1978). *Family therapy in clinical practice*. Jason Aronson.

Braun, V., & Clarke, V (2012) Thematic Analysis. In Cooper, H. (Ed.) *APA Handbook of Research Methods in Psychology: Vol. 2. Research Designs* (pp.57-71). American Psychological Association.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Braun, V., & Clarke, V. (2016). (Mis) conceptualising themes, thematic analysis, and other problems with Fugard and Potts’ (2015) sample-size tool for thematic analysis. *International Journal of social research methodology*, *19*(6), 739-743.

Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative research in sport, exercise and health*, *13*(2), 201-216.

Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide*. SAGE Publications.

Brinkmann, S. (2016). *Diagnostic cultures: A cultural approach to the pathologization of modern life*. Routledge.

British Psychological Society Ethics Committee (2018). *Code of Ethics and Conduct*. British Psychological Society

Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: a worked example. *Journal of health services research & policy*, *7*(4), 209-215.

Brown, J. (2018). Parents' experiences of their adolescent's mental health treatment: Helplessness or agency-based hope. *Clinical Child Psychology and Psychiatry*, *23*(4), 644-662.

Burr, V. (1998). Overview: Realism, relativism, social constructionism and discourse. *Social constructionism, discourse and realism*, *18*, 13-26.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness*, *4*(2), 167-182.

Busfield, J. (2017). The concept of medicalisation reassessed. *Sociology of Health & Illness*, *39*(5), 759-774.

Campbell, R., Pound, P., Pope, C., Britten, N., Pill, R., Morgan, M., & Donovan, J. (2003). Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social science & medicine*, *56*(4), 671-684.

Carpenter, B., & Towers, C. (2008). Recognising fathers: The needs of fathers of children with disabilities. *Support for learning*, *23*(3), 118-125.

Carroll, C., Booth, A., Leaviss, J., & Rick, J. (2013). "Best fit" framework synthesis: refining the method. *BMC medical research methodology*, *13*(1), 37.

Carter, B. E., & McGoldrick, M. E. (1988). *The changing family life cycle: A framework for family therapy*. Gardner Press.

Chalmers, A. F. (1999). *What is this thing called science?* Hackett Publishing.

Clarke, V., & Braun, V. (2017). Commentary: Thematic analysis. *Journal of Positive Psychology*, *12*(3), 297-298.

Clement, Sarah, Oliver Schauman, Tanya Graham, Francesca Maggioni, Sara Evans-Lacko, Nikita Bezborodovs, Craig Morgan, Nicolas Rüsch, June SL Brown, and Graham Thornicroft. "What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies." Psychological medicine 45, no. 1 (2015): 11-27.

Cluley, V., Martin, G., Radnor, Z., & Banerjee, J. (2021). Frailty as biographical disruption. *Sociology of Health & Illness*, *43*(4), 948-965.

Coffey, J. S. (2006). Parenting a child with chronic illness: a metasynthesis. *Pediatric nursing*, *32*(1).

Coolhart, D., Ritenour, K., & Grodzinski, A. (2018). Experiences of ambiguous loss for parents of transgender male youth: A phenomenological exploration. *Contemporary Family Therapy*, *40*(1), 28-41.

Cooper, R. (2018). *Diagnosing the diagnostic and statistical manual of mental disorders*. Routledge. (Original work published 2014).

Cornish, D., & Owen-Williams, R. (2021). *Deaths registered in England and Wales: 2020*. Office for National Statistics. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2020

Cortazzi, M. (2001). Narrative analysis in ethnography. *Handbook of ethnography*, 384-394.

Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: a systematic review. *Journal of pediatric psychology*, *38*(8), 809-828.

Cramer, D., & Howitt, D. (2020). Research Methods in Psychology (6th ed.). Pearson.

Crenna-Jennings, W., & Hutchinson, J. (2020). *Access to child and adolescent mental health services in 2019*. Education Policy Institute. https://epi.org.uk/wp-content/uploads/2020/01/Access-to-CAMHS-in-2019_EPI.pdf

Creswell, J. W. (2013). Steps in conducting a scholarly mixed methods study.

Creswell, J. W., & Poth, C. N. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). SAGE publications.

Critical Appraisal Skills Programme (2018). CASP Qualitative Checklist. https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018_fillable_form.pdf

Crouch, L., Reardon, T., Farrington, A., Glover, F., & Creswell, C. (2019). “Just keep pushing”: Parents' experiences of accessing child and adolescent mental health services for child anxiety problems. *Child: Care, Health and Development*, *45*(4), 491-499.

Dahl, C. M., & Boss, P. (2020). Ambiguous loss: Theory-based guidelines for therapy with individuals, families, and communities. *The Handbook of Systemic Family Therapy*, *4*, 127-151.

Darmi, E., Bellali, T., Papazoglou, I., Karamitri, I., & Papadatou, D. (2017). Caring for an intimate stranger: parenting a child with psychosis. *Journal of psychiatric and mental health nursing*, *24*(4), 194-202.

Davies, J. (2022). *Sedated: How Modern Capitalism Caused our Mental Health Crisis*. Atlantic Books.

De Souza, R. (2021). *The state of children’s mental health services 2019/20*. https://www.childrenscommissioner.gov.uk/report/mental-health-services-2019-20/

Del-Pino-Casado, R., Priego-Cubero, E., López-Martínez, C., & Orgeta, V. (2021). Subjective caregiver burden and anxiety in informal caregivers: A systematic review and meta-analysis. *PloS one*, *16*(3), e0247143.

Department for Work and Pensions. (2021). Family Resources Survey: financial year 2019 to 2020. https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2019-to-2020/family-resources-survey-financial-year-2019-to-2020#care-1

Department of Health. (2015). *Future in mind: Promoting, protecting and improving our children and young people’s mental health and wellbeing*. NHS England. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414024/Childrens_Mental_Health.pdf

Dixon-Woods, M., Bonas, S., Booth, A., Jones, D. R., Miller, T., Sutton, A. J., Shaw, R. L., Smith, J. A., & Young, B. (2006). How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative research*, *6*(1), 27-44.

Donnelly, P. L. (2001). Korean American family experiences of caregiving for their mentally ill adult children: An interpretive inquiry. *Journal of Transcultural Nursing*, *12*(4), 292-301.

Eakes, G. G. (1995). Chronic sorrow: The lived experience of parents of chronically mentally ill individuals. *Archives of Psychiatric Nursing*, *9*(2), 77-84.

Eakes, G. G., Burke, M. L., & Hainsworth, M. A. (1998). Middle-range theory of chronic sorrow. *Image: The Journal of Nursing Scholarship*, *30*(2), 179-184.

Ellis, C., & Bochner, A. (1992). Telling and performing personal stories. *SAGE Publishing.*

Erskine, H. E., Baxter, A. J., Patton, G., Moffitt, T. E., Patel, V., Whiteford, H. A., & Scott, J. G. (2017). The global coverage of prevalence data for mental disorders in children and adolescents. *Epidemiology and psychiatric sciences*, *26*(4), 395-402.

Ezzy, D. (2000). Illness narratives: time, hope and HIV. *Social science & medicine*, *50*(5), 605-617.

Ferguson, S. L. (2022). Teaching What Is "Real" About Science. *Science & Education*, 1-19.

Fletcher, G. J. (1996). Realism versus relativism in psychology. *The American journal of psychology*, 409-429.

Flores, M. R. (2021). *Impact of Ambiguous Loss on Couples with a Partner Affected by a Traumatic Brain Injury: A Critical Literature Analysis*. [Doctoral dissertation, Azusa Pacific University].

Frank, A. W. (2010). In defence of narrative exceptionalism. *Sociology of Health and Illness.*

Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics*. University of Chicago Press. (Original work published 1995).

Fraser, H. (2004). Doing narrative research: Analysing personal stories line by line. *Qualitative social work*, *3*(2), 179-201.

Freedman, R., Lewis, D. A., Michels, R., Pine, D. S., Schultz, S. K., Tamminga, C. A., Gabbard, G. O., Gau, S. S., Javitt, D. C., Oquendo, M. A., Shrout, P. E., Vieta, E., & Yager, J. (2013). The initial field trials of DSM-5: new blooms and old thorns. *American Journal of Psychiatry*, *170*(1), 1-5.

GBD 2019 Mental Disorders Collaborators. (2022). Global, regional, and national burden of 12 mental disorders in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet Psychiatry*, *9*(2), 137-150.

Gee, J. P. (1986). Units in the production of narrative discourse. *Discourse processes*, *9*(4), 391-422.

Gee, J. P. (1991). A linguistic approach to narrative. *Journal of narrative and life history*, *1*(1), 15-39.

George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *The gerontologist*, *26*(3), 253-259.

Gergen, K. J., & Gergen, M. M. (1986). Narrative form and the construction of psychological science.

Goodman, N. (1983). “Realism, relativism, and reality.” *New Literary History,* 14*(2)*, 269-272.

Gough, D., Thomas, J., & Oliver, S. (2012). Clarifying differences between review designs and methods. *Systematic reviews*, *1*(1), 1-9.

Gray, R. E., Fergus, K. D., & Fitch, M. I. (2005). Two Black men with prostate cancer: A narrative approach. *British Journal of Health Psychology*, *10*(1), 71-84.

Greenhalgh, T., Robert, G., Macfarlane, F., Bate, P., Kyriakidou, O., & Peacock, R. (2005). Storylines of research in diffusion of innovation: a meta-narrative approach to systematic review. *Social science & medicine*, *61*(2), 417-430.

Haefner, J. (2014). An application of Bowen family systems theory. *Issues in mental health nursing*, *35*(11), 835-841.

Hainsworth, M. A., Eakes, G. G., & Burke, M. L. (1994). Coping with chronic sorrow. *Issues in Mental Health Nursing*, *15*(1), 59-66.

Harden, J. (2005a). “Uncharted waters”: The experience of parents of young people with mental health problems. *Qualitative Health Research*, *15*(2), 207-223.

Harden, J. (2005b). Parenting a young person with mental health problems: Temporal disruption and reconstruction. *Sociology of health & illness*, *27*(3), 351-371.

Herbert, E., & Carpenter, B. (1994). Fathers – the secondary partners: Professional perceptions and fathers' reflections. *Children & Society*, *8*(1), 31-41.

Hoffman, L. (1981). *Foundations of family therapy: A conceptual framework for systems change*. Basic Books.

https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2020#age-standardised-mortality-rates-by-sex

Human Rights Council. (2017). *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.* United Nations General Assembly. https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/076/04/PDF/G1707604.pdf?OpenElement

i-THRIVE. (2019). *National i-THRIVE Programme Executive Summary.* http://implementingthrive.org/wp-content/uploads/2019/07/National-i-THRIVE-Programme-Executive-Summary-FINAL.pdf

Jacoby, R., Benveniste, S., & Goldzweig, G. (2021). Illness as experienced by parents of children with end-stage renal disease: the “Ill Unit”. *Illness, Crisis & Loss*, *29*(3), 205-219.

Jenks, E. B. (2005). Explaining disability: Parents’ stories of raising children with visual impairments in a sighted world. *Journal of contemporary ethnography*, *34*(2), 143-169.

Jennings, H., Slade, M., Bates, P., Munday, E., & Toney, R. (2018). Best practice framework for Patient and Public Involvement (PPI) in collaborative data analysis of qualitative mental health research: methodology development and refinement. *BMC psychiatry*, *18*(1), 1-11.

Johansson, A., Anderzen-Carlsson, A., Åhlin, A., & Andershed, B. (2010). Mothers' everyday experiences of having an adult child who suffers from long-term mental illness. *Issues in Mental Health Nursing*, *31*(11), 692-699.

Johansson, A., Anderzen-Carlsson, A., Åhlin, A., & Andershed, B. (2012). Fathers’ everyday experiences of having an adult child who suffers from long-term mental illness. *Issues in Mental Health Nursing*, *33*(2), 109-117.

Johnstone, L., & Dallos, R. (2014). *Formulation in psychology and psychotherapy*. London: Routledge.

Jorm, A. F., Patten, S. B., Brugha, T. S., & Mojtabai, R. (2017). Has increased provision of treatment reduced the prevalence of common mental disorders? Review of the evidence from four countries. *World Psychiatry*, *16*(1), 90-99.

Kanungpiarn, T., Tungpunkom, P., Kantaruksa, K., & Chaloumsuk, N. (2021). Hopeful Endless Caring to Maintain Normal Life: A Grounded Theory of Thai Mothers’ Caring for Adult Children with Schizophrenia. *Pacific Rim International Journal of Nursing Research*, *25*(2), 171-184.

Kapust, L. R. (1982). Living with dementia: The ongoing funeral. *Social Work in Health Care*, *7*(4), 79-91.

Karp, D. A. (1994). Living with depression: Illness and identity turning points. *Qualitative health research*, *4*(1), 6-30.

Karp, D. A. (2002). *The burden of sympathy: How families cope with mental illness*. Oxford University Press, USA.

Karp, D. A., & Tanarugsachock, V. (2000). Mental illness, caregiving, and emotion management. *Qualitative health research*, *10*(1), 6-25.

Kazak, A. E. (1989). Families of chronically ill children: a systems and social-ecological model of adaptation and challenge. *Journal of consulting and clinical psychology*, *57*(1), 25.

Kerr, M. E., Bowen, M., & Kerr, M. E. (1988). *Family evaluation*. WW Norton & Company.

Kerr, S. M., & McIntosh, J. B. (2000). Coping when a child has a disability: exploring the impact of parent-to-parent support. *Child: care, health and development*, *26*(4), 309-322.

Kinderman, P., Read, J., Moncrieff, J., & Bentall, R. P. (2013). Drop the language of disorder. *BMJ Ment Health*, *16*(1), 2-3.

Knafl, K., & Zoeller, L. (2000). Childhood chronic illness: A comparison of mothers' and fathers' experiences. *Journal of Family Nursing*, *6*(3), 287-302.

Knowles, G., Gayer-Anderson, C., Turner, A., Dorn, L., Lam, J., Davis, S., Blakey, R., Lowis, K., Schools Working Group, Young Persons Advisory Group, Pinfold, V., Creary, N., Dyer, J., Hatch, S. L., Ploubidis, G., Bhui, K., Harding, S. & Morgan, C. (2022). Covid-19, social restrictions, and mental distress among young people: a UK longitudinal, population-based study. *Journal of child psychology and psychiatry, 63*(11), 1392-1404.

Krendl, A. C., & Pescosolido, B. A. (2020). Countries and cultural differences in the stigma of mental illness: the east–west divide. *Journal of Cross-Cultural Psychology*, *51*(2), 149-167.

Kumar, K., & Gupta, M. (2014). Clinical and socio-demographic determinants of psychological health and burden in family caregivers of patients with unipolar depression. *Asian journal of psychiatry, 9*, 51-56.

Lange, K. W., Reichl, S., Lange, K. M., Tucha, L., & Tucha, O. (2010). The history of attention deficit hyperactivity disorder. *ADHD Attention Deficit and Hyperactivity Disorders*, *2*(4), 241-255.

Law, E., Fisher, E., Eccleston, C., & Palermo, T. M. (2019). Psychological interventions for parents of children and adolescents with chronic illness. *Cochrane Database of Systematic Reviews*, (3).

Law, M., King, S., Stewart, D., & King, G. (2002). The perceived effects of parent-led support groups for parents of children with disabilities. *Physical & Occupational Therapy in Pediatrics*, *21*(2-3), 29-48.

Lawrence, L. P. (2011). *Through my mother's eyes: The lifelong journey of raising children with and without disabilities.* [Doctoral dissertation, University of Denver].

Lawrence, P. J., Parkinson, M., Jasper, B., Creswell, C., & Halligan, S. L. (2021). Supporting the parents of children and young people with anxiety and depressive disorders is an opportunity not to be missed: a scoping review. *The Lancet Psychiatry*, *8*(10), 909-918.

Lazaratou, H., Anagnostopoulos, D. C., Alevizos, E. V., Haviara, F., & Ploumpidis, D. N. (2007). Parental attitudes and opinions on the use of psychotropic medication in mental disorders of childhood. *Annals of General Psychiatry*, *6*(1), 1-7.

Leavy, P. (Ed.). (2014). *The Oxford handbook of qualitative research*. Oxford University Press, USA.

Lindgren, C. L., Burke, M. L., Hainsworth, M. A., & Eakes, G. G. (1992). Chronic sorrow: A lifespan concept. *Scholarly Inquiry for Nursing Practice*, *6*(1), 27-40.

Locock, L., Ziebland, S., & Dumelow, C. (2009). Biographical disruption, abruption and repair in the context of motor neurone disease. *Sociology of health & illness*, *31*(7), 1043-1058.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British journal of psychology*, *91*(1), 1-20

Mahat-Shamir, M. (2022). Neither here nor there and a little bit of both: The ambiguous loss experience of parents who lost a baby to sudden infant death syndrome. *Death Studies*, *46*(5), 1186-1195.

Marshall, B., Cardon, P., Poddar, A., & Fontenot, R. (2013). Does sample size matter in qualitative research?: A review of qualitative interviews in IS research. *Journal of computer information systems*, *54*(1), 11-22.

Martin, F., Clyne, W., Pearce, G., & Turner, A. (2019). Self-management support intervention for parents of children with developmental disorders: The role of gratitude and hope. *Journal of Child and Family Studies*, *28*, 980-992.

McAuliffe, R., O'Connor, L., & Meagher, D. (2014). Parents' experience of living with and caring for an adult son or daughter with schizophrenia at home in Ireland: a qualitative study. *Journal of psychiatric and mental health nursing*, *21*(2), 145-153.

McCormack, C., & McCann, E. (2015). Caring for an adolescent with anorexia nervosa: parent’s views and experiences. *Archives of Psychiatric Nursing*, *29*(3), 143-147.

McPherson, S., & Oute, J. (2021). Responsibilisation of caregivers in depression: the limitations of policy-based evidence. *Social Theory & Health*, *19*(4), 347-361.

Mechling, B. M., Ahern, N. R., & Palumbo, R. (2018). Applying ambiguous loss theory to children of parents with an opioid use disorder. *Journal of Child and Adolescent Psychiatric Nursing*, *31*(2-3), 53-60.

Milliken, P. J. (2001). Disenfranchised mothers: Caring for an adult child with schizophrenia. *Health Care for Women International*, *22*(1-2), 149-166.

Mohr, W. K., & Regan-Kubinski, M. J. (2001). Living in the fallout: Parents' experiences when their child becomes mentally ill. *Archives of Psychiatric Nursing*, *15*(2), 69-77.

Murray, M. (1999). The storied nature of health and illness. *Qualitative health psychology: Theories and methods*, 47-63.

Newlove-Delgado T, Marcheselli F, Williams T, Mandalia D, Davis J, McManus S, Savic M, Treloar W, Ford T. (2022). Mental Health of Children and Young People in England, 2022. *NHS Digital.*

NHS. (2021). How to care for children with complex needs. https://www.nhs.uk/conditions/social-care-and-support-guide/caring-for-children-and-young-people/how-to-care-for-children-with-complex-needs/

NHS Benchmarking Network. (2021). *Children and Young People's Mental Health Services Workforce Report for Health Education England, National Report.* East London NHS Foundation Trust.

NHS Digital. (2021). Reference Tables, Table 1.2. Mental Health Bulletin 2019-20 Annual Report. https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-bulletin/2019-20-annual-report

NHS England. (2020). NHS commissioning - Who is considered a carer? https://www.england.nhs.uk/commissioning/comm-carers/carers/

NHS England. (2014). *Five Year Forward View*. https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

NHS England. (2018). Child and Adolescent Mental Health Services (CAMHS) Tier 4: General adolescent services including specialist eating disorder services. *Service Specification.* https://www.england.nhs.uk/wp-content/uploads/2018/02/tier-4-camhs-general-adolescent-service-specification-v3.pdf

NHS England. (2019). *The NHS Long Term Plan.* https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

NHS Health Advisory Service. (1995). *Together We Stand: Thematic review of the Commissioning, Role and Management of Child and Adolescent Mental Health Services*. London: The Stationery Office.

Nicholas, D. B., Lach, L., King, G., Scott, M., Boydell, K., Swaatzky, B., Reisman, J., Schippel, E., & Young, N. J. (2010). Contrasting internet and face – to – face focus group for children with chronic health conditions: Outcomes and participant experiences. *International Journal of Qualitative Methods, 9*(1). 105-121.

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies*. SAGE.

Nola, R. (Ed.). (1988). *Relativism and realism in science*. Klumer Academic Publishers.

O'Connor, C., & Joffe, H. (2020). Intercoder reliability in qualitative research: debates and practical guidelines. International journal of qualitative methods, 19, 1609406919899220.

O'Hare, D., Eapen, V., Grove, R., Helmes, E., McBain, K., & Reece, J. (2017). Youth with Tourette syndrome: parental perceptions and experiences in the Australian context. *Australian Journal of Psychology*, *69*(1), 48-57.

Office for National Statistics (ONS). (2022). *Ethnic Group, national identity, language and religion: Overview*. Census 2021. https://census.gov.uk/census-2021-results/phase-one-topic-summaries/ethnic-group-national-identity-language-and-religion

Office for National Statistics. (2017). Unpaid carers provide social care worth £57 billion - Office for National Statistics. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/articles/unpaidcarersprovidesocialcareworth57billion/2017-07-10

Okrey Anderson, S., & McGuire, J. K. (2021). "I feel like God doesn't like me": Faith and Ambiguous Loss Among Transgender Youth. *Family Relations*, *70*(2), 390-401.

Olfson, M., Gameroff, M. J., Marcus, S. C., & Jensen, P. S. (2003). National trends in the treatment of attention deficit hyperactivity disorder. *American Journal of Psychiatry, 160*(6), 1071-1077.

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social casework*, *43*(4), 190-193.

Oute, J., & Huniche, L. (2017). Who gets involved with what? A discourse analysis of gender and caregiving in everyday family life with depression. *Outlines. Critical Practice Studies*, *18*(1), 05-27.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hrobjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., McGuinness, L. A., ... Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *Systematic reviews*, *10*(1), 1-11.

Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H., & Sourtzi, P. (2007). Caring for a relative with dementia: family caregiver burden. *Journal of advanced nursing*, *58*(5), 446-457.

Patrick-Ott, A., & Ladd, L. D. (2010). The blending of Boss's concept of ambiguous loss and Olshansky's concept of chronic sorrow: A case study of a family with a child who has significant disabilities. *Journal of Creativity in Mental Health*, *5*(1), 73-86.

Patton, M. Q. (2015). *Qualitative research & evaluation methods: Integrating theory and practice*. Sage publications., 4th Ed. London: SAGE.

Pauline, B., & Boss, P. (2009). *Ambiguous loss: Learning to live with unresolved grief*. Harvard University Press.

Pejlert, A. (2001). Being a parent of an adult son or daughter with severe mental illness receiving professional care: parents' narratives. *Health & Social Care in the Community*, *9*(4), 194-204.

Peytrignet, S., Marszalek, K., Grimm, F., Thorlby, R., & Wagstaff, T. (2022). *Children and Young People's Mental Health*. The Health Foundation. https://www.health.org.uk/news-and-comment/charts-and-infographics/children-and-young-people-s-mental-health

Pidgeon, N., & Henwood, K. (1997). Using grounded theory in psychological research. *Doing qualitative analysis in psychology*, *12*.

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological journal*, *20*(1), 7-14.

Piuva, K., & Brodin, H. (2020). Just like any other family? Everyday life experiences of mothers of adults with severe mental illness in Sweden. *Community mental health journal*, *56*, 1023-1032.

Poindexter, C. C. (2003). The ubiquity of ambiguity in research interviewing: an exemplar. *Qualitative Social Work*, *2*(4), 383-409.

Poindexter, C. C. (2004). Medical profiling: narratives of privilege, prejudice, and HIV stigma. *Qualitative Health Research*, *14*(4), 496-512.

Polanczyk, G. V., Salum, G. A., Sugaya, L. S., Caye, A., & Rohde, L. A. (2015). Annual research review: A meta‐analysis of the worldwide prevalence of mental disorders in children and adolescents. *Journal of child psychology and psychiatry*, *56*(3), 345-365.

Polkinghorne, D. E. (1988). *Narrative knowing and the human sciences*. Suny Press.

Poonnotok, P., Thampanichawat, W., Patoomwan, A., & Sangon, S. (2016). Struggling to restore normalcy: Thai parents' experiences in being caregivers of children with early schizophrenia. *Pacific Rim International Journal of Nursing Research*, *20*(1), 71-84.

Preyde, M., VanDonge, C., Carter, J., Lazure-Valconi, K., White, S., Ashbourne, G., Penney, R., Frensch, K., & Cameron, G. (2015). Parents of youth in intensive mental health treatment: Associations between emotional and behavioral disorders and parental sense of competence. *Child and Adolescent Social Work Journal*, *32*(4), 317-327.

Priestley, J., & McPherson, S. (2016). Experiences of adults providing care to a partner or relative with depression: A meta-ethnographic synthesis. *Journal of Affective Disorders*, *192*, 41-49.

Priestley, J., McPherson, S., & Davies, F. (2018). Couples' disease: the experience of living with a partner with chronic depression. *Journal of Couple & Relationship Therapy*, *17*(2), 128-145.

Raymond, K. Y., Willis, D. G., & Sullivan-Bolyai, S. (2017). Parents caring for adult children with serious mental illness. *Journal of the American Psychiatric Nurses Association*, *23*(2), 119-132.

Reardon, T., Harvey, K., Baranowska, M., O'Brien, D., Smith, L., & Creswell, C. (2017). What do parents perceive are the barriers and facilitators to accessing psychological treatment for mental health problems in children and adolescents? A systematic review of qualitative and quantitative studies. *European child & adolescent psychiatry*, *26*(6), 623-647.

Reeve, J., Lloyd-Williams, M., Payne, S., & Dowrick, C. (2010). Revisiting biographical disruption: exploring individual embodied illness experience in people with terminal cancer. *Health:*, *14*(2), 178-195.

Riessman, C. K. (1993). *Narrative analysis* (Vol. 30). SAGE Publications.

Riessman, C. K., & Quinney, L. (2005). Narrative in social work: A critical review. *Qualitative social work*, *4*(4), 391-412.

Rose, N. (2006). Disorders without borders? The expanding scope of psychiatric practice. *BioSocieties*, *1*(4), 465-484.

Royal College of Psychiatrists. (2021). Record number of children and young people referred to mental health services as pandemic takes its toll. https://www.rcpsych.ac.uk/news-and-features/latest-news/detail/2021/09/23/record-number-of-children-and-young-people-referred-to-mental-health-services-as-pandemic-takes-its-toll

Sadler, K., Vizard, T., Ford, T., Marchesell, F., Pearce, N., Mandalia, D., Davis, J., Brodie, E., Forbes, N., Goodman, A., Goodman, R., & McManus, S. (2018). Mental health of children and young people in England, 2017. *NHS Digital.*

Salzman, H. (2022). The Myth of Closure: Ambiguous Loss in a Time of Pandemic and Change. *Family Medicine*, *54*(3), 235-236.

Sarrió-Colas, L., Ferré-Grau, C., Monteso-Curto, P., Adell-Lleixà, M., Albacar-Riobóo, N., & Lleixá-Fortuño, M. (2022). The experiences of parents as caregivers of adolescents with mental illnesses, the impact of the crisis and the admission to a day hospital. *Archives of psychiatric nursing*, *37*, 45-51.

Sartor, T., Lange, S., & Tröster, H. (2023). Cumulative Stress of Single Mothers-An Exploration of Potential Risk Factors. *The Family Journal*, *31*(1), 88-94.

Schene, A. H. (1990). Objective and subjective dimensions of family burden. *Social Psychiatry and Psychiatric Epidemiology*, *25*(6), 289-297.

Scheyett, A. (1990). The oppression of caring: Women caregivers of relatives with mental illness. *Affilia*, *5*(1), 32-48.

Scottish Government. (2017). *Mental Health Strategy 2017-2027. Prevention and early intervention.* Population Health Directorate.

Siddaway, A. P., Wood, A. M., & Hedges, L. V. (2019). How to do a systematic review: a best practice guide for conducting and reporting narrative reviews, meta-analyses, and meta-syntheses. *Annual review of psychology*, *70*, 747-770

Smith, J. A., & Osborn, M. (2008). Chapter 4: Interpretative phenomenological analysis. In L. Yardley, & J. A. Smith (Eds.), *Qualitative Psychology: A Practical Guide to Research Methods. Second Edition.* SAGE Publications.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. SAGE Publications.

Solmi, M., Radua, J., Olivola, M., Croce, E., Soardo, L., Salazar de Pablo, G., Shin, J., Kirkbride, J. B., Jones, P., Kim, J. H., Kim, J. Y., Carvalho, A. F., Seeman, M. V., Correll, C. U., & Fusar-Poli, P. (2021). Age at onset of mental disorders worldwide: large-scale meta-analysis of 192 epidemiological studies. *Molecular psychiatry*, 1-15.

Stapley, E., Midgley, N., & Target, M. (2016). The experience of being the parent of an adolescent with a diagnosis of depression. *Journal of Child and Family Studies*, *25*, 618-630.

Stiles, W. B. (1993). Quality control in qualitative research. *Clinical psychology review*, *13*(6), 593-618.

Svensson, E., Nilsson, K., Levi, R., & Suarez, N. C. (2013). Parents' experiences of having and caring for a child with an eating disorder. *Eating disorders*, *21*(5), 395-407.

Tawfik, G. M., Dila, K. A. S., Mohamed, M. Y. F., Tam, D. N. H., Kien, N. D., Ahmed, A. M., & Huy, N. T. (2019). A step by step guide for conducting a systematic review and meta-analysis with simulation data. *Tropical medicine and health*, *47*(1), 4.

The British Psychological Society. (2011). *Society's critical response to DSM-5*. https://thepsychologist.bps.org.uk/volume-24/edition-8/news

The British Psychological Society. (2013). *Classification of behaviour and experience in relation to functional psychiatric diagnoses: Time for a paradigm shift. DCP Position Statement*. The British Psychological Society.

The King's Fund. (2022). Social care 360: expenditure. https://www.kingsfund.org.uk/publications/social-care-360/expenditure

Thomas-MacLean, R. (2004). Understanding breast cancer stories via Frank's narrative types. *Social science & medicine*, *58*(9), 1647-1657.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology*, *8*(1), 1-10.

Thomson, S., Marriott, M., Telford, K., Law, H., McLaughlin, J., & Sayal, K. (2014). Adolescents with a diagnosis of anorexia nervosa: Parents' experience of recognition and deciding to seek help. *Clinical child psychology and psychiatry*, *19*(1), 43-57.

Todd, S., & Jones, S. (2005). Looking at the future and seeing the past: the challenge of the middle years of parenting a child with intellectual disabilities. *Journal of Intellectual Disability Research*, *49*(6), 389-404.

Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., & Barker, K. (2014). Meta-ethnography 25 years on: challenges and insights for synthesising a large number of qualitative studies. *BMC medical research methodology*, *14*(1), 1-14.

Tuck, I., Du Mont, P., Evans, G., & Shupe, J. (1997). The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing*, *11*(3), 118-125.

Uzark, K., & Jones, K. (2003). Parenting stress and children with heart disease. *Journal of pediatric health care,* 17(4), 163-168.

Van den Kieboom, R., Snaphaan, L., Mark, R., & Bongers, I. (2020). The trajectory of caregiver burden and risk factors in dementia progression: A systematic review. *Journal of Alzheimer's Disease*, *77*(3), 1107-1115.

Voort, J. L. V., He, J. P., Jameson, N. D., & Merikangas, K. R. (2014). Impact of the DSM-5 attention-deficit/hyperactivity disorder age-of-onset criterion in the US adolescent population. *Journal of the American Academy of Child & Adolescent Psychiatry, 53(7), 736-744.*

Wade, J. (2006). "Crying alone with my child:" Parenting a school age child diagnosed with bipolar disorder. *Issues in Mental Health Nursing*, *27*(8), 885-903.

Waite, P., Pearcey, S., Shum, A., Raw, J. A., Patalay, P., & Creswell, C. (2021). How did the mental health symptoms of children and adolescents change over early lockdown during the COVID-19 pandemic in the UK? *JCPP advances*, *1*(1), e12009.

Walker, M. T. (2006). The social construction of mental illness and its implications for the recovery model. *International Journal of Psychosocial Rehabilitation*, *10*(1), 71-87.

Whitehead, L. C. (2006). Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Social science & medicine*, *62*(9), 2236-2245.

Whitney, C.-J., & Jo Hutchinson. (2018). *Access to Children and Young People's Mental Health Services - 2018*. Education Policy Institute. https://epi.org.uk/publications-and-research/access-to-camhs-2018/

Widnall, E., Winstone, L., Mars, B., Haworth, C., & Kidger, J. (2020). Young people's mental health during the COVID-19 pandemic: Initial findings from a secondary school survey study in South West England. *National Institute for Health Research School for Public Health Research*.

Wiens, S. E., & Daniluk, J. C. (2009). Love, loss, and learning: The experiences of fathers who have children diagnosed with schizophrenia. *Journal of Counseling & Development*, *87*(3), 339-348.

Willig, C. (1999). Beyond appearances: A critical realist approach to social constructionism. *Social constructionist psychology: A critical analysis of theory and practice*, 37-51.

Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method.* Open University Press.

Willingham-Storr, G. L. (2014). Parental experiences of caring for a child with intellectual disabilities: A UK perspective. *Journal of Intellectual Disabilities*, *18*(2), 146-158.

Wing, L., & Potter, D. (2002). The epidemiology of autistic spectrum disorders: is the prevalence rising?. *Mental retardation and developmental disabilities research reviews*, *8*(3), 151-161.

Wolpert, M., Harris, R., Hodges, S., Fuggle, P., James, R., Wiener, A., McKenna, C., Law, D., York, A., Jones, M., Fonagy, P., Fleming, I., & Munk, S. (2019). THRIVE framework for system change. https://repository.tavistockandportman.ac.uk/1933/1/Thrive-framework-for-system-change-2019.pdf

Wolpert, M., Harris, R., Hodges, S., Fuggle, P., James, R., Wiener, A., McKenna, C., Law, D., York, A., Jones, M., & Fonagy, P. (2015). THRIVE elaborated. https://repository.tavistockandportman.ac.uk/1447/1/Wolpert%20-%20Thrive%20elaborated.pdf

World Health Organization. (2014). *Health for the world's adolescents: a second chance in the second decade: summary* (No. WHO/FWC/MCA/14.05). World Health Organization. https://apps.who.int/iris/bitstream/handle/10665/112750/WHO?sequence=1

World Health Organization. (2019). *International Classification of Diseases* (11th Ed.). https://www.who.int/standards/classifications/classification-of-diseases

Zarit, S.H., Reever, K.E., Bach-Peterson, J., 1980. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 20 (6) 649–655.

Zoom Video Communications, Inc. (2022). Zoom (Version 5.11.6) [Zoom]. Zoom Video Communications, Inc.

Appendices

Appendix A

Quality Appraisal of Studies (CASP, 2018)

	Armitage et al., 2020	Bai et al., 2020	Darmi et al., 2017	Donnelly, 2001	Gok & Duyan, 2020	Harden 2005a	Harden 2005b	Johansson et al., 2010	Johansson et al., 2012	Kanungpiarn et al., 2021	McAuliffe et al., 2014	McCormack & McCann, 2015
1. Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4. Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
5. Was the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
6. Has the relationship between researcher and participants been adequately considered?	Y	U	U	U	U	Y	Y	Y	Y	Y	Y	Y
7. Have ethical issues been taken into consideration?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
8. Was the data analysis sufficiently rigorous?	Y	Y	Y	U	U	Y	Y	Y	Y	Y	Y	Y
9. Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Note. Y = Yes, N = No, U = Unclear

	Mohr & Regan-Kubinski, 2001	O'Hare et al., 2017	Pejlert, 2001	Piuva & Brodin, 2020	Poonnotok et al., 2016	Raymond et al., 2017	Sarrió -Colasa et al., 2022	Stapley et al., 2016	Svensson et al., 2013	Thomson et al., 2014	Tuck et al., 1997	Wade, 2006	Wiens & Daniluk, 2009
1. Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4. Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
5. Was the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
6. Has the relationship between researcher and participants been adequately considered?	Y	Y	U	Y	Y	Y	Y	Y	U	U	Y	U	Y
7. Have ethical issues been taken into consideration?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	U
8. Was the data analysis sufficiently rigorous?	U	Y	Y	U	Y	Y	Y	Y	Y	Y	Y	U	Y
9. Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Note. Y = Yes, N = No, U = Unclear

Appendix B

Tables of Methodology (Meta-Ethnographic Synthesis)

Methodology	**Armitage et al., 2020**	**Bai et al., 2020**	**Darmi et al., 2017**	**Donnelly, 2001**	**Gok & Duyan, 2020**
Aim	To explore mothers' experiences of having an adolescent child with depression	To explore the challenges of parents caring for their children with early stage schizophrenia in China	To explore parents' lived experience of caring for a child with psychosis	To gain an understanding of Korean American families' caregiving experiences for their mentally ill grown children	To evaluate the lives of parents of children with schizophrenia and to determine the perceptions, feelings and thoughts of parents about the processes they experienced.
Country	UK	China	Greece	USA (Korean Americans)	Turkey
Health setting	Community	-	Inpatient and Community	Community	Community
Sample	8 mothers of children aged 13–18	13 parents (9 mothers, 4 fathers) of children aged 13-18	16 parents (14 mothers, 2 fathers) of adult children aged 20 and above (upper limit not specified)	7 parents (5 mothers, 2 fathers) of adult children (ages not specified)	30 parents (15 mothers and 15 fathers) of children (age not specified, unclear if adults or under 18s)
Mental illness	Depression	Schizophrenia	Psychotic Disorder	Schizophrenia, Major Depressive Disorder, or Bipolar Disorder with Severe Psychotic Features	Schizophrenia
Data collection	Interviews	Interviews	Interviews	Interviews	Interviews

Methodology	Harden 2005a	Harden 2005b	Johansson 2010	Johansson 2012	Kanungpiarn 2021
Aim	To address the experience of parents caring for a young person with mental health problems	To explore the experiences of parents living with a young person with mental health problems	To describe the everyday life experiences of mothers of an adult child with long-term mental illness	To describe the everyday life experiences of fathers of adult children with various forms of long-term mental illness	To explore north-eastern Thai mothers' adaptation processes in taking care of their adult children with schizophrenia
Country	Scotland	Scotland	Sweden	Sweden	Thailand
Health setting	-	-	Community	Community	Community
Sample	25 parents (18 mothers, 7 fathers) of children aged 13 to 16	25 parents (18 mothers, 7 fathers) of children aged 13 to 16	16 mothers of adult children aged 18-49	10 fathers of adult children aged 18-43	20 mothers of adult children (age not specified)
Mental illness	Diagnosed mental illnesses (not specified)	Various mental illnesses (not specified)	Various mental illnesses	Various mental illnesses	Schizophrenia
Data collection	Interviews	Interviews	Interviews	Interviews	Interviews

Methodology	**McAuliffe 2014**	**McCormack & McCann 2015**	**Mohr & Regan-Kubinski 2001**	**O'Hare 2017**	**Pejlert 2001**
Aim	To explore the experience of parents living with and caring for their adult children with schizophrenia	To investigate the subjective experiences of parents in caring for an adolescent diagnosed with anorexia nervosa	To capture the process through which parents journey when they are faced with the mental illness of their child	To explore and identify the multidimensional stressors associated with parenting a child or adolescent with Tourette's Syndrome in the Australian context	To illuminate the meaning of parental caregiving of a son or daughter with severe mental illness living in a care setting
Country	Ireland	Ireland	USA	Australia	Sweden
Health setting	Community	Community	-	Community	Residential Care
Sample	6 parents (5 mothers, 1 father) of adult children aged 27-45	10 parents (7 mothers, 3 fathers) of adolescents (ages not specified)	8 parents (4 mothers, 4 fathers) of adult children aged 17-31	22 mothers of children aged 7-19	8 parents (4 mothers, 4 fathers) of adult children aged 30-47
Mental illness	Schizophrenia	Anorexia Nervosa	Schizophrenia or a Major Affective Disorder	Tourette's Syndrome	Schizophrenia
Data collection	Interviews	Interviews	Focus groups	Interviews	Interviews

Methodology	**Piuva & Brodin 2020**	**Poonnotok, et al. 2016**	**Raymond, Willis & Sullivan-Bolyai 2017**	**Sarrio-Colasa et al 2022**	**Stapley, Midgley & Target 2016**
Aim	To explore the experiences of mothers in Sweden who care for adult children suffering from serious mental illnesses	To explore parental caregiving processes in Thailand during the early phase of schizophrenia.	To examine parents' management styles when caring for adult children with serious mental illness and parents' perspectives on what type of community-based mental health interventions would support and/or enhance overall family functioning.	To analyse the caregiving experiences of parents whose adolescent children with a mental illness require admission to a day treatment hospital for mental health services	To examine the experience of being the parent of an adolescent who had recently been referred to CAMHS in the UK and diagnosed with moderate to severe depression.
Country	Sweden	Thailand	USA	Spain	UK
Health setting	-	Inpatient and Community	Inpatient and Community	'Day Hospital'	Community
Sample	15 mothers of adult children aged 20-50	25 parents (17 mothers, 8 fathers) of adult children aged 16-47	30 parents (22 mothers, 8 fathers) of adult children aged 22-58	18 parents (11 mothers, 7 fathers) of children aged 12-17	48 parents (40 mothers, 8 fathers) of children aged 11-17
Mental illness	'Serious mental illness' (not specified)	Schizophrenia	Schizophrenia, Schizoaffective Disorder, Bipolar Disorder	Various mental illnesses	Depression
Data collection	Interviews	Interviews	Interviews	Interviews	Interviews

Methodology	**Svensson et al 2013**	**Thomson et al 2014**	**Tuck 1997**	**Wade 2006**	**Wiens & Daniluk 2009**
Aim	To explore the lived experience of having a child with an eating disorder	To investigate parents' experiences of recognising that their child had an eating problem and deciding to seek help	To explore the phenomenon of caring for an adult child with schizophrenia	To describe the lived experience of parents of elementary school age children who have been diagnosed with Bipolar Disorder	To provide a greater understanding of the experience of fathering a young adult child with schizophrenia
Country	Sweden	UK	USA	USA	Canada
Health setting	'Intensive Specialist Treatment'	Community	-	-	Community
Sample	10 parents (6 mothers, 4 fathers) of children aged 16-18	8 parents (7 mothers, 1 father) of children aged 11-18	9 parents (7 mothers, 2 fathers) of adult children (ages not specified)	10 'parents' (primary caregivers; 7 female, 3 male) of children aged 6-11 years	6 fathers of adult children aged 18-35
Mental illness	Anorexia Nervosa, Eating Disorder Not Otherwise Specified	Anorexia Nervosa	Schizophrenia/Schizoaffective Disorder	Bipolar Disorder	Schizophrenia
Data collection	Interviews	Interviews	Interviews	Interviews	Interviews

Appendix C

Tables of Key Concepts (Meta-Ethnographic Synthesis)

Key Concepts	**Armitage et al., 2020**	**Bai et al., 2020**
Transformation of the loved child	Depression causes change; there is a sense of loss (loss of connection, loss of personality, change in family interactions)	The child was not the same as before his/her illness
A psychological tsunami of emotions	Keeping their emotions hidden and under control in order to help the situation;	Psychological shock and emotional burden
Realisation	-	Parents were overwhelmed by the initial diagnosis of schizophrenia
Getting help	Not knowing who can help; predominantly negative experiences of help-seeking	Parents maintained there was still a gap of knowledge regarding schizophrenia and caring skills in the home
Gendered caregiving	-	-
Commitment	-	-
An impossible task	fragility of the situation and the potentially disastrous effect of a weak moment	Caring for a patient with mental illness is an onerous task
Uncertain future	Inability to predict what may happen, and the potential destruction that may occur	Parents are afraid that the children would not have the ability to adapt to society and life
Reframing thinking	-	-
Finding meaning	-	-
Second-order theory	Mothers subjugate their emotions in order to help their child	The one-child policy (China) means that the only child becomes the focus of the family and holds all hopes and dreams; "parents were haunted by psychological shock" at the time of diagnosis

Key Concepts	Darmi et al., 2017	Donnelly, 2001
Transformation of the loved child	Caring for an intimate stranger. Unable to recognise their son or daughter; a relationship to a frightening stranger	
A psychological tsunami of emotions	Pervasive guilt; mixed feelings of fear, anger and sadness	Suffering as a way of life; intolerable pain
Realisation	After an acute episode or the official diagnosis they come to terms with the reality of their son's or daughter's disorder	Realisation of mental illness after traditional healing methods no longer effective
Getting help	A cruel but necessary treatment	Cultural factors contributed to failure to use mental health resources appropriately
Gendered caregiving	-	mothers, particularly, grieved for their daughters
Commitment	An unending commitment and a huge burden; self-sacrifice. Trapped in a role of incessant caring	Parents placed their children's needs before their own which overshadowed their lives with the overwhelming responsibility; caring for their mentally ill children and feeling trapped with no hope of escaping their situations
An impossible task	The disorder was described as an unknown, threatening experience with unpredictable outcomes, over which parents had no control	Battling the disease of incompetence; their commitment to become caregivers was a long process of suffering
Uncertain future	The thought of the patient's care after their death was a source of anxiety and ongoing concern	Grieving for the loss of dreams and pleasures in their children's success and happiness
Reframing thinking	-	Shifting their view of suffering through prayer and spirituality
Finding meaning	In search of meaning; making sense of what was happening was important in their striving to rebuild their relationship with their child and assume a new parenting role	Moving beyond ordinary caregiving experiences toward finding unique personal meanings, expanding caregivers' consciousness
Second-order theory	"An anxious-ambivalent parent-child relationship is redefined over the course of the illness trajectory"	"Cultural factors contributed to […] failure to use mental health resources appropriately" but these same cultural factors helped participants to transcend their pain in a journey towards spirituality

Key Concepts	**Gok & Duyan, 2020**	**Harden 2005a**
Transformation of the loved child	-	The changes taking place in their child were beyond the normal range of parents' experience
A psychological tsunami of emotions	Anger, pity, loneliness, burnout, shame, fear, helplessness	Failing as parents
Realisation	After the diagnosis of the disease, a great majority of parents question themselves and life	A renegotiation of the parental caregiving role
Getting help	Parents felt that health professionals should be more thoughtful and sensitive to the patient and family	Not being listened to by the medical profession; excluded from care
Gendered caregiving	The support of the spouses to each other is very empowering for mothers who take almost all care responsibilities of the child	-
Commitment	-	A sense of failure at being unable to fulfil their role
An impossible task	Feelings of helplessness and uncertainty in parents begin to increase as the disease process progresses	Helpless parenting. Helpless not simply as carers but also as parents, faced with situations for which prior parenting skills/expertise did not equip them
Uncertain future	Loss of dreams; the child is an individual who gives parents the possibility to make the dreams that they could not live out in their lifetime come true.	Parents try to build on their knowledge and experience as a form of reskilling
Reframing thinking	The existential questioning of parents helps them to recognise their own strengths and weaknesses	Presenting a very positive image of a family that had suffered and, though still suffering, had found a way to cope by accepting the situation
Finding meaning	the parents' devotion to God or the value/meanings they give to anything may allow parents to find meaning in the difficulties that they experienced	-
Second-order theory	Physical, social, cognitive, emotional and spiritual experiences affect the empowerment processes of parents	a "dialectic of control revolving around the dual themes of deskilling and reskilling": parents resented the intrusion of expert knowledge and were simultaneously critical of the limited intervention they received"

Key Concepts	**Harden 2005b**	**Johansson 2010**
Transformation of the loved child	The illness seemed to change the child's personality	Loss of the beloved child. Constant sorrow due to the child's disease-related personality changes
A psychological tsunami of emotions	Guilt played an important role in the parents' narratives of the early stages of the illness	Mothers learned to live with a constant sadness
Realisation	Transition to adulthood was not one of increasing independence	Awareness of the child's diagnosis facilitated an understanding of the child's behaviour, and the mothers' worries often decreased if they were familiar with the symptoms
Getting help	Sharing responsibility with healthcare professionals causes conflict	Despite their need for support, several mothers were uncertain about where they could obtain it
Gendered caregiving	responsibility for care was gendered; the mother was always the primary carer; most of the fathers described their role in the care of their child as supportive or secondary to that of their wife	-
Commitment	the process of 'stepping back' was not regarded as an option	The adult child who is living with mental illness is always on their mind
An impossible task	Conflict between their extended parental caregiving responsibility and their responsibility to care for themselves	Living a life under constant strain
Uncertain future	concern was not only for the future life experiences of their child but also the implications for their own lives and the future they had imagined they would have	The mothers' everyday lives seemed to waver between hope and despair. Despite their parental situation, several mothers were reflective and optimistic and able to see light in the darkness
Reframing thinking	Presenting a very positive image of a family that had suffered and, though still suffering, had found a way to cope by accepting the situation	Living in the present. A good insight into the disease made the mothers feel more secure in their mothering role and they dared to trust their ability to handle the situation
Finding meaning	-	Seeing light in the darkness despite difficulties
Second-order theory	"Parents were engaged in the process of narratively reconstructing their life histories as parents; centring on the reconstruction of their past, present and future role of parents and revolving around the issue of responsibility"	"Long-term and repeated painful experiences made the mothers patient and hardened in order to protect themselves, which probably made them stronger"

Key Concepts	**Johansson 2012**	**Kanungpiarn 2021**
Transformation of the loved child	Despair as this wasn't how they imagined their child's future	They thought their son or daughter looked like a stranger, like a person controlled by a supernatural power, a ghost, or black magic.
A psychological tsunami of emotions	Frustration and a sense of insufficiency	Participants used techniques to try to maintain a state of positive emotions when caring for children with schizophrenia
Realisation	-	As the mothers combined treatments, they also learned that modern treatments could improve their children's symptoms
Getting help	Mental health professionals took little interest in the fathers' caregiving role and they felt themselves to be ignored and that they were an unused resource	Mothers had a strong hope that their child would return to normal life and used every means to get them cured: supernatural rituals, modern treatments, and combined treatments
Gendered caregiving	Fathers described the mother as carrying the heaviest burden	-
Commitment	A constant struggle that required both strength and courage	No matter what happened, they had to stay together with their ill children and take care of each other for the rest of their lives
An impossible task	Feelings of powerlessness emerged in the fathers' descriptions of their everyday lives, they expressed despair and resignation and their determination to do the best for their child was not always sufficient. The fathers experienced their own ability to alleviate their child's distress and provide support as deficient	Hopeful endless caring to maintain normal life
Uncertain future	Uncertainty as part of everyday life	Mothers had hope to restore balance, and restoring self-balance seemed to be the new start of their new normal life
Reframing thinking	-	Mothers reframed their existing way of thinking about their child and the caregiving situation by deliberately re-considering situations and by lowering expectations. Mothers also applied Buddhism beliefs
Finding meaning	-	-
Second-order theory	"Maintaining a strong façade while balancing on a thin line". "Fathers were actively involved in their child's daily life"	Mothers engage in a process of "hopeless endless caring to maintain normal life", supported by cultural and spiritual practices

Key Concepts	**McAuliffe 2014**	**McCormack & McCann 2015**
Transformation of the loved child	A yearning for a return of the child they once had	The illness 'takes over'
A psychological tsunami of emotions	Psychological tsunami: utter devastation. Loss, sorrow, pity, grief, sadness and regret	emotionally drained
Realisation	The diagnosis as a psychological tsunami	-
Getting help	Lack of understanding; doctors and mental health professionals failed to recognise the symptoms	GPs remained unaware. Positive experience with other service providers
Gendered caregiving	-	For the most part, mothers undertook this role (managing/supervising the adolescent) as they were traditionally at home with the adolescent
Commitment	Parents at no point thought of abdicating their caregiving role or leaving their offspring with schizophrenia. AND No parent complained of feeling ‘burdened’ or used the word ‘burden’	Regardless of the cost of care or the personal sacrifices they had to make, the adolescent's care was always the priority
An impossible task	Sometimes the stress was too much for fathers, and it was detrimental to their own psychological wellbeing	-
Uncertain future	The future was viewed as a mixture of hope, uncertainty, and as 'never ending'	A fundamental part of the recovery process is hope
Reframing thinking	Their love for their offspring seemed unconditional, and it helped them to see the positive side of their situation	Recognising positive aspects to the illness
Finding meaning	Identifying a purpose in life. They found a new meaning to their caring role. They also found their caregiving role as rewarding and especially when their son or daughter reciprocated their love	
Second-order theory	"After the struggles of the initial post-diagnosis period, they adjusted to their caregiving role and identified a purpose in life"	"No aspect of the family life remained unaffected"

Key Concepts	**Mohr & Regan-Kubinski 2001**	**O'Hare 2017**
Transformation of the loved child	the report of family members that their child had changed and there was no going back	Grief and loss of the 'ideal child'
A psychological tsunami of emotions	Anguish; emotionally shredded, disconcerting emptiness and devoid of power	Living worried
Realisation	Ranged from gradual perception to sudden realization. The process of awareness: initial questioning, the realization, and feelings of impending crisis. A collapse of defences	Diagnosis experienced as a highly traumatic major life event for mothers
Getting help	Sequelae which do not give closure	The importance of connecting with those who 'get it', such as peers, parents, and understanding medical professionals or teachers
Gendered caregiving	-	Mother assumes the burden of care
Commitment	They became overwhelmed at having to live with the vicissitudes of watching their children's descent into mental illness - there was no escape or avoidance of the truth	Mothers forced to take charge, advocate, become the expert
An impossible task	Parents came to see themselves as strangers who have been cast into a world that was painfully foreign and unresponsive to their needs, wishes or parental strivings. Devoid of power	Parenting dilemmas
Uncertain future	Fear centred on what could have been or what could be	Difficulty maintaining a sense of optimism regarding a normal future for both child and mother
Reframing thinking	-	-
Finding meaning	-	-
Second-order theory	"the report of family members that their child had changed, that there was no going back, suggests that trigger events that maintain the cycle of sorrow were typical experiences of these families"	Twelve distinct major stressors for parents of children with TS, with the majority of mothers assuming the burden of care of their child in addition to the role of child advocate and TS expert

Key Concepts	Pejlert 2001	Piuva & Brodin 2020
Transformation of the loved child	Child has changed but a core part of self not influenced by changes. The 'old' child could be glimpsed and this endorsed hope Sorrow for the lost child	neither the child nor the family was like other families
A psychological tsunami of emotions	Living with sorrow, anguish, constant worry, guilt and shame	mourning, loss, and the sense of a never-ending burden were central themes in the mothers' descriptions
Realisation	Time before the illness and the time after the onset of the illness	The first time the mothers began to realise that there was something different with their children
Getting help	Encountering psychiatric care awakened feelings of guilt	Experiences with psychiatric care were mixed and often depended on the year in which the child became ill
Gendered caregiving	-	-
Commitment	Denial/resistance to information about likely poor outcome of the illness	-
An impossible task	Endless parenting, encompassing care-giving responsibilities and worries about the child	The mothers were continually confronting new problems and new situations along the way
Uncertain future	Hoping for a better life for the child	The future suddenly appeared as beyond control, unpredictable and dangerous
Reframing thinking	Concentrating on positive aspects of life and being involved in one's own interests, acceptance of the illness and the hope for a better lifestyle for the child	An alternative perspective included change of values, perceptions and new approaches towards life
Finding meaning	Communion in family and church	Their experiences had helped them to distinguish between small and big issues in life.
Second-order theory	Parents live with chronic sorrow and have long, difficult relationships with health professionals	"Discourses and practices of sanism have affected families and mothers have fought against both oppression and discriminatory actions"

Key Concepts	Poonnotok, Thampanichawat, Patoomwan & Sangon 2016	Raymond, Willis & Sullivan-Bolyai 2017
Transformation of the loved child	The participants' realisation that the pre-illness normal state of their children would never be restored	Parents were confronted with caring for their child who was now acting differently
A psychological tsunami of emotions	Feelings of love, sympathy, and extreme pity	family in turmoil
Realisation	The diagnosis means facing shattered dreams	Decision to act: child's behaviour escalating to beyond the parent's ability to control the situation
Getting help	Searching for information about the illness by discussing with other parent relatives, reading, or watching health programmes	A long journey ranging from months to years to obtain an accurate psychiatric diagnosis for their child. Mental health services were not easily accessible
Gendered caregiving	Thai society expects women to be family caregivers; some fathers distanced themselves from caregiving	-
Commitment	Caregiving as an unavoidable role	All parents acknowledged that the child's serious mental illness dominated family life; they described their focus shifting from managing the family as a whole to managing the chaos created by the illness
An impossible task	Parents distanced themselves from caregiving in order to decrease the intensity of their struggle to restore the child's normalcy	The child's behaviour escalated to beyond the parent's ability to control the situation
Uncertain future	Maintain caregiving with new perspectives. They experienced anxiety when they thought about the future and their role as caregiver	Not wanting to lose hope for their child's future while wanting to be realistic. Fears for the future.
Reframing thinking	They adjusted their previous expectation that their children would have a normal life	Making adjustments in the expectations and goals they had for their adult child after being diagnosed
Finding meaning	Thai culture, Buddhist principles and a positive appraisal of the caregiving role help Thai caregivers to overcome distress	-
Second-order theory	"Struggling to restore normalcy" is family caregivers' coping response to a chronic mental illness and normalcy is also the goal of caregiving in early schizophrenia	Caregiving experience involves "multiple phases that were lengthy, arduous, and emotion-laden as parents learned to manage the impact of serious mental illness"

Key Concepts	**Sarrio-Colasa et al 2022**	**Stapley, Midgley & Target 2016**
Transformation of the loved child	Parents wanted to get back the child who had been lost	Changes in the way they had been parenting their child; the need to give extra parenting to their child
A psychological tsunami of emotions	-	emotional turmoil
Realisation	A decisive moment for parents came when their children refused to go to school, and the subsequent scrutiny of their own skills as parents triggered the intervention of the use of social services	Realising the extent of their child's difficulties
Getting help	A long road which includes ambivalence and delayed diagnosis	Lack of support
Gendered caregiving	Mothers experienced the admission as an abrupt separation and fathers tended to adopt a more positive attitude	
Commitment	-	They had to parent their child more now than they should need to at their child's age
An impossible task	Loss of parental authority	Feelings of self-doubt about their parenting prowess and parenting practices that had arisen as a result of being unable to help their child
Uncertain future	The future looked uncertain. Some parents did not consider the future and had trouble talking about it	Worried and anxious about the future
Reframing thinking	-	-
Finding meaning	Hoping or attempting to regain the meaning of life	-
Second-order theory	"Caregiving experiences of parents are met with many barriers: accessing care, the difficulty of recognising mental illness in adolescents, internalised stigma, fear of the possible consequences of being recognised, lack of therapeutic alliance with professionals, disagreements with diagnosis and emotional shock at self-destructive behaviours"	Caring for a child with a mental illness requires "Parenting in overdrive"

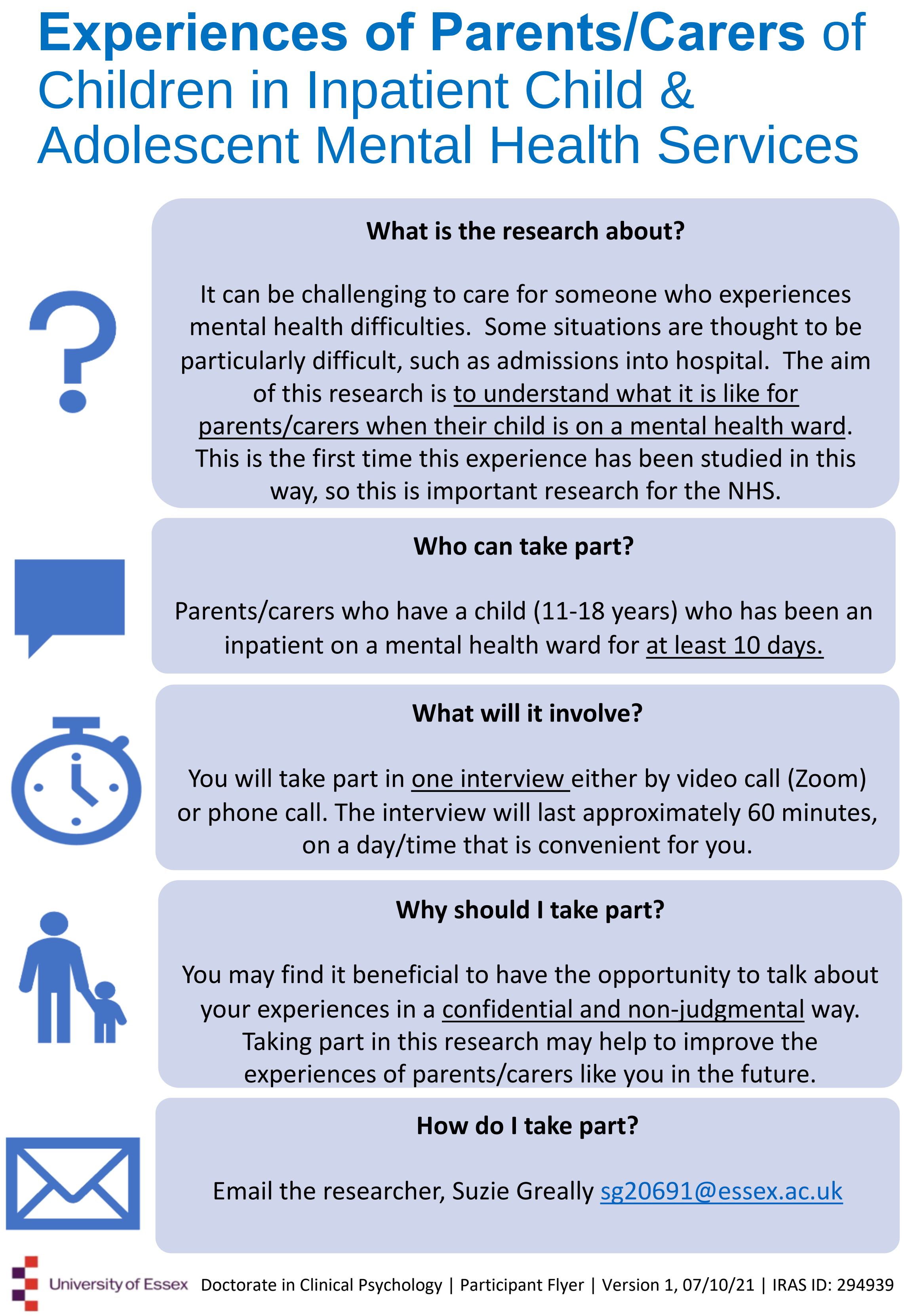
Key Concepts	**Svensson et al 2013**	**Thomson et al 2014**
Transformation of the loved child	Parents felt that they acted as if they were again caring for a toddler	Secrecy and deception amongst adolescents
A psychological tsunami of emotions	Worry, anger, guilt and shame	-
Realisation	-	once parents recognised that their child had an eating problem
Getting help	Positive experiences of talking to health professionals at the treating clinic	The process of help-seeking by the parents reflected a cycle of avoidance
Gendered caregiving	Support from the spouse was vital to some of the parents	-
Commitment	-	-
An impossible task	Powerless towards the illness; no matter how hard they tried, the child failed to improve and sometimes became sicker. Impossible and hopeless	Paradoxical situation: parents and GPs unable to act without the child admitting their difficulties. Feelings of powerlessness
Uncertain future	Worry for the future of the child, e.g. that the child would have to struggle with the sequels of the condition for a long time, and worries that the child would relapse or die. Parents expressed that they were able to carry the hope that their child would get well and ultimately grow strong from the disease	-
Reframing thinking	Faith in the inherent ability of the family and in one's competence as a parent	-
Finding meaning	-	-
Second-order theory	Parents felt powerless towards the illness but found ways to cope	Three stages towards help-seeking: normalisation of early changes; ambivalence; decision point for help-seeking

Key Concepts	**Tuck 1997**	**Wade 2006**
Transformation of the loved child	The loved and cherished child has not died, but is changed A core identity, an unchanged and enduring individual can occasionally be glimpsed	Child treated by others as a delinquent instead of a child with a mental illness
A psychological tsunami of emotions	uncertainty and helplessness, fear and anxiety	Distressing loneliness due to feeling judged, blamed, and excluded
Realisation	The temporal life world. Time was linear and sharply divided into before and after the diagnosis	Time of diagnosis was a pivotal moment and experienced with relief
Getting help	A desperate search for someone who could suggest both an explanation and a remedy for the disturbing behaviours their child	Healthcare professionals were described as unknowledgeable, uncaring and inattentive
Gendered caregiving	-	-
Commitment	The needs of the person with schizophrenia supersede the cherished goals and values of the caregiver	These parents feel like they have no choice if they are to help their child
An impossible task	Caring for a child with schizophrenia involves watching, protecting, seeking help, and the sacrifice of personal needs	The immense task of parenting consumed all of their time, chaotic and unplanned, from minute to minute, extending into year to year. Time is an embodied experience, felt as engulfing and suffocating
Uncertain future	Hope is inseparable from the risk of disappointment Hope sustained the participant in the struggle to care for this adult child, and exposed the parent to disappointment and renewed grief Constantly changing levels of hope	Faith in the possibility of a future cure. Fear of what the future may bring
Reframing thinking	Reassess their ideas about the nature of the world and beliefs about the meaning of life	A strong sense of commitment and hope, "it's worth it" and positives outweigh the negatives
Finding meaning	Philosophical or spiritual comfort	The child makes it all worth while
Second-order theory	"The experience of caring […] is grounded in a changed temporal world"	"Being a parent […] means experiencing unrelenting fear, frustration, loneliness and hurt" but "the child, the prime consideration of the parent's life, makes it all worth while"

Key Concepts	**Wiens & Daniluk 2009**
Transformation of the loved child	Loss of who their child once was
A psychological tsunami of emotions	A sense of devastation, vulnerability, sadness and loss
Realisation	The sense of devastation and vulnerability experienced by fathers as they became aware of the realities of living with schizophrenia for their families
Getting help	Frustration with the mental health system
Gendered caregiving	-
Commitment	In looking ahead, all of the participants reflected on their responsibility to provide and plan for their child's future
An impossible task	Devastation and vulnerability as they began to face the realities of living with a child with schizophrenia
Uncertain future	Loss of hopes and dreams for their child's future
Reframing thinking	Admiration for their child's courage and strength
Finding meaning	Fathers gained a greater understanding of themselves as fathers, and reflected on how they gained personally through discovering the depths of their love for their child
Second-order theory	Fathers formed a "profound admiration" and a "deeper commitment to the relationship they had with their child" through "reflecting on, and making meaning of, their experiences of fathering their mentally ill children"

Appendix D

Recruitment Flyer



Experiences of Parents/Carers of Children in Inpatient Child & Adolescent Mental Health Services

What is the research about?

It can be challenging to care for someone who experiences mental health difficulties. Some situations are thought to be particularly difficult, such as admissions into hospital. The aim of this research is to understand what it is like for parents/carers when their child is on a mental health ward. This is the first time this experience has been studied in this way, so this is important research for the NHS.

Who can take part?

Parents/carers who have a child (11-18 years) who has been an inpatient on a mental health ward for at least 10 days.

What will it involve?

You will take part in one interview either by video call (Zoom) or phone call. The interview will last approximately 60 minutes, on a day/time that is convenient for you.

Why should I take part?

You may find it beneficial to have the opportunity to talk about your experiences in a confidential and non-judgmental way. Taking part in this research may help to improve the experiences of parents/carers like you in the future.

How do I take part?

Email the researcher, Suzie Greally sg20691@essex.ac.uk

University of Essex Doctorate in Clinical Psychology | Participant Flyer | Version 1, 07/10/21 | IRAS ID: 294939

Appendix E

Template Email for Recruitment

Suggested email subject: Research Opportunity for Parents/Carers

Dear [NAME],

I hope this email finds you well.

A Trainee Clinical Psychologist is undertaking research about the **experiences of parents/carers who have a child in an inpatient CAMHS ward** as part of her Doctorate in Clinical Psychology. This research may help to improve the experiences of parents in the future.

She would like to speak to parents in a one-off interview via Zoom or phone call. **Please see the attached flyer** for more information.

Please email Suzie directly (sg20691@essex.ac.uk) if you are interested in participating, would like to hear more about the research or have an informal phone call.

Thank you.

Kind regards,
[NAME]

Appendix F

Participant Information Sheet

University of Essex
School of Health and Social Care
Doctorate in Clinical Psychology

Colchester Campus
Wivenhoe Park
Colchester
Essex
CO4 3SQ

IRAS ID: 294939
Participant Identification Number: --

PARTICIPANT INFORMATION SHEET

Experiences of Parents/Carers of Children in Inpatient Child and Adolescent Mental Health Services

Principal Investigator: **Suzanna Greally**

You have been invited to participate in a research study. In order to help you decide whether or not you would like to take part, we would like to explain what the research involves and why it is being carried out. Please ask if you have any questions.

Summary
The aim of this research is to explore the experiences of parents who have a child who is receiving treatment in an inpatient child and adolescent mental health ward.
We would like to understand what it is like to be a parent to a child with mental illness, and what it is like when that child is admitted into a mental health ward. We hope to understand how inpatient admission affects parents, so that, in the future, services can know more about how parents feel and know how to support them.
We will be interviewing 20 parents of children across four different adolescent wards in England.

Parents and/or primary caregivers can take part in this research.

What would taking part involve?
This study involves one interview, either on Zoom (videocall) or by phone. The interview will take approximately 60-90 minutes. Breaks can be taken during the interview if required. You will also be asked to complete a form to provide basic information about yourself and your child, and you will need to sign a consent form before your interview.
You can choose to be interviewed by yourself, or with your partner.

What are the possible disadvantages and risks of taking part?
In the interview, you will be asked questions about your child, your family, and your experience of your child’s inpatient admission. We may talk about whether your own physical and mental health has been affected by your child’s illness and their inpatient admission. Some of this might feel upsetting or difficult to talk about.
The interviewer is a Trainee Clinical Psychologist who is experienced in talking to families of young people with mental health difficulties. She also has experience of working in services similar to the ward in which your child is receiving treatment, including other inpatient adolescent wards.

University of Essex
School of Health and Social Care
Doctorate in Clinical Psychology

Colchester Campus
Wivenhoe Park
Colchester
Essex
CO4 3SQ

The interview should feel informal, friendly and entirely non-judgemental. Importantly, you do not have to answer any of the questions if you do not want to.

What are the possible benefits of taking part?

You may find it beneficial to have a chance to talk about your experience. It may feel useful and cathartic to be able to speak openly in a setting which is non-judgemental and confidential.

We also hope that through conducting this research, we will understand more about parents' experiences. This might mean that benefits will be experienced by other parents in a similar situation to you, in the future, as a consequence of this research.

What should I do if I want to take part?

If you would like to take part in this research please email the Principal Investigator, Suzanna Greally, sg20691@essex.ac.uk. Please provide your phone number in the email. Suzanna will then arrange a time to speak to you to answer any questions you may have, and schedule an interview. Please note that a maximum of twenty people will be interviewed, so it is possible that you will not be invited for an interview if more than twenty people apply.

Please note that your child will need to be an inpatient on the adolescent ward at the time of your interview, or have been very recently discharged (within 10 days).

Please note that only those who can communicate in spoken English will be able to take part.

What will happen to the results of the research study?

The interview will be audio-recorded and transcribed by the researcher so that it can be analysed.

The research will be written up as a thesis in part fulfilment of the Doctorate in Clinical Psychology and a manuscript will also be prepared for publication in a scientific journal. The results of the research may also be presented at a conference.

The results of the research will therefore be in the public domain. However, all results will be completely anonymised so that neither you nor your child will be identifiable. Any person mentioned in the interview will be given a pseudonym in the transcript, and care will be taken to ensure that any combination of information (e.g. age, ethnicity, occupation) cannot be used to identify anyone.

If you would like to receive a copy of the results of the research, please inform the principal investigator (contact details below).

Will my information be kept confidential?

Yes, your participation in the study and all information that you provide will remain confidential. Individuals who agree to participate will be given a unique participant number to protect their anonymity. This, and other data will be stored on an encrypted file on a password-protected computer. Any hard data copies will be scanned onto a computer and then shredded. The researcher will transcribe your interview into text format and the audio recording will then be destroyed. Fully anonymised direct quotations from your interview may be used in the thesis write-up. This will not include identifiable data. Only the researcher and the research supervisor will have access to the data.

University of Essex
School of Health and Social Care
Doctorate in Clinical Psychology

Colchester Campus
Wivenhoe Park
Colchester
Essex
CO4 3SQ

What are the limits of confidentiality?

The only exception when confidentiality would be broken is if you say something in your interview which suggests that you, or another person, may be at risk of harm. In the unlikely event that this happens, the principal investigator will have a duty to inform the inpatient team.

What is the legal basis for using the data and who is the Data Controller?

We (The University of Essex) need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. Universities and the NHS are funded from taxes and we are expected to do research as part of our job. We need to be able to prove that we need to use patient data for research. In legal terms, this means that we use data as part of a task in the public interest. The legal basis for processing your data is through public interest.

The Data Controller is the University of Essex and the contact is the University Information Assurance Manager (dpo@essex.ac.uk).

Where can you find out more about how your information is used?

You can find out more about how we use your information at https://www.hra.nhs.uk/information-about-patients/, our leaflet available from www.hra.nhs.uk/patientdataandresearch, by asking one of the research team or by sending an email to the University of Essex's data protection officer: dpo@essex.ac.uk.

Which ethics review body has reviewed the study?

This research has been reviewed by the NHS Health Research Authority.

What if I have a concern or complaint?

If you have any concerns or a complaint about any aspect of the research, in the first instance please contact the principal investigator of the project, Suzanna Greally, using the contact details below. If you are still concerned, you think your complaint has not been addressed to your satisfaction, or you feel that you cannot approach the principal investigator, please contact the departmental Director of Research in the department responsible for this project, Dr Susan McPherson (smcpher@essex.ac.uk). If you are still not satisfied, please contact the University's Research Governance and Planning Manager, Sarah Manning-Press (sarahm@essex.ac.uk).

You can also contact the Patient Advice and Liaison Service (PALS) at the appropriate NHS Trust to discuss any concerns and receive confidential advice, information and support:

Appendix G

Demographic Information Sheet

University of Essex
School of Health and Social Care
Doctorate in Clinical Psychology

Colchester Campus
Wivenhoe Park
Colchester
Essex
CO4 3SQ

IRAS ID: 294939
Participant Identification Number: __

DEMOGRAPHIC INFORMATION

Title of Research: **Experiences of Parents/Carers of Children in Inpatient Child and Adolescent Mental Health Services**

Chief Investigator: **Suzanna Greally**

Participant (Parent/Carer)

Age: …………

Gender: …………

Ethnicity: *Please choose one option from the table overleaf that best describes your ethnic group or background, and write the corresponding number here:* ………..

Marital status: single / married / separated / divorced / widowed / co-habiting

Co-parenting: yes / no

Number of children (including child receiving inpatient treatment): …………

Average weekly contact with child receiving inpatient treatment (hours): <1 / 1-5 / 6-15 / 16-35 / >35

Occupation: ……………..……

Employment: full time / part time / unemployed / retired / student / other: …………

Participant's Child

Age: …………

Gender: …………

Ethnicity: *Please choose one option from the table overleaf that best describes your child's ethnic group or background, and write the corresponding number here*: ………

Duration of mental health difficulties: ……………..

Diagnosis: ……………..

Number of days in unit at time of interview (approximately): …………

Number of admissions to previous units (if applicable): …………

University of Essex
School of Health and Social Care
Doctorate in Clinical Psychology

Colchester Campus
Wivenhoe Park
Colchester
Essex
CO4 3SQ

White	1. English/Welsh/Scottish/Northern Irish/British 2. Irish 3. Gypsy or Irish Traveller 4. Any other White background, please describe
Mixed/Multiple ethnic groups	5. White and Black Caribbean 6. White and Black African 7. White and Asian 8. Any other Mixed/Multiple ethnic background, please describe
Asian/Asian British	9. Indian 10. Pakistani 11. Bangladeshi 12. Chinese 13. Any other Asian background, please describe
Black/ African/Caribbean/Black British	14. African 15. Caribbean 16. Any other Black/African/Caribbean background, please describe
Other ethnic group	17. Arab 18. Any other ethnic group, please describe

Appendix H

Extract from Reflexive Log

March 2022, after first interview:

I didn’t really use the topic guide. She had so much to say. Early in the interview I felt myself getting anxious when I thought that I wasn’t exactly getting the information that I was looking for (such as stories about the child’s education). But actually, these stories are still significant – I can think about why she was choosing to tell those stories. What was the significance of those stories for her? What was she conveying to me? What story were we co-constructing? I also realised towards the end of the interview that virtually all the topics on my topic guide had been covered – this happened without me needing to direct the interview very much.

I had been worried that if might be difficult to ensure that these interviews didn’t resemble therapy sessions. I wasn’t sure whether it would be hard to respond differently in this context compared to how I would if the participants were clients in therapy. But I’m pleased that this definitely did not feel like therapy. It felt like a research interview. However, she said that she felt comfortable talking to me and alluded, at the end of her interview, to it being good to talk. I think this might connect to the fact that I did draw on some skills that I might also use in therapy. I think it’s okay for me to be empathetic in the interviews; I nodded my head to show agreement, I demonstrated when I was surprised or interested, and I framed the interview by stating at the beginning that I’m interested in parents’ experiences and feelings and recognise that inpatient admissions affect the whole family. I think it would have felt unethical for me to expect these participants to speak about such difficult experiences without me showing any empathy or without giving them any sort of encouragement to continue talking. I know that other researchers would approach interviews differently, but I think my approach is in line with my epistemology. I can acknowledge in the write-up too that I co-construct the interviews with each participant, and that their stories are versions of truths.

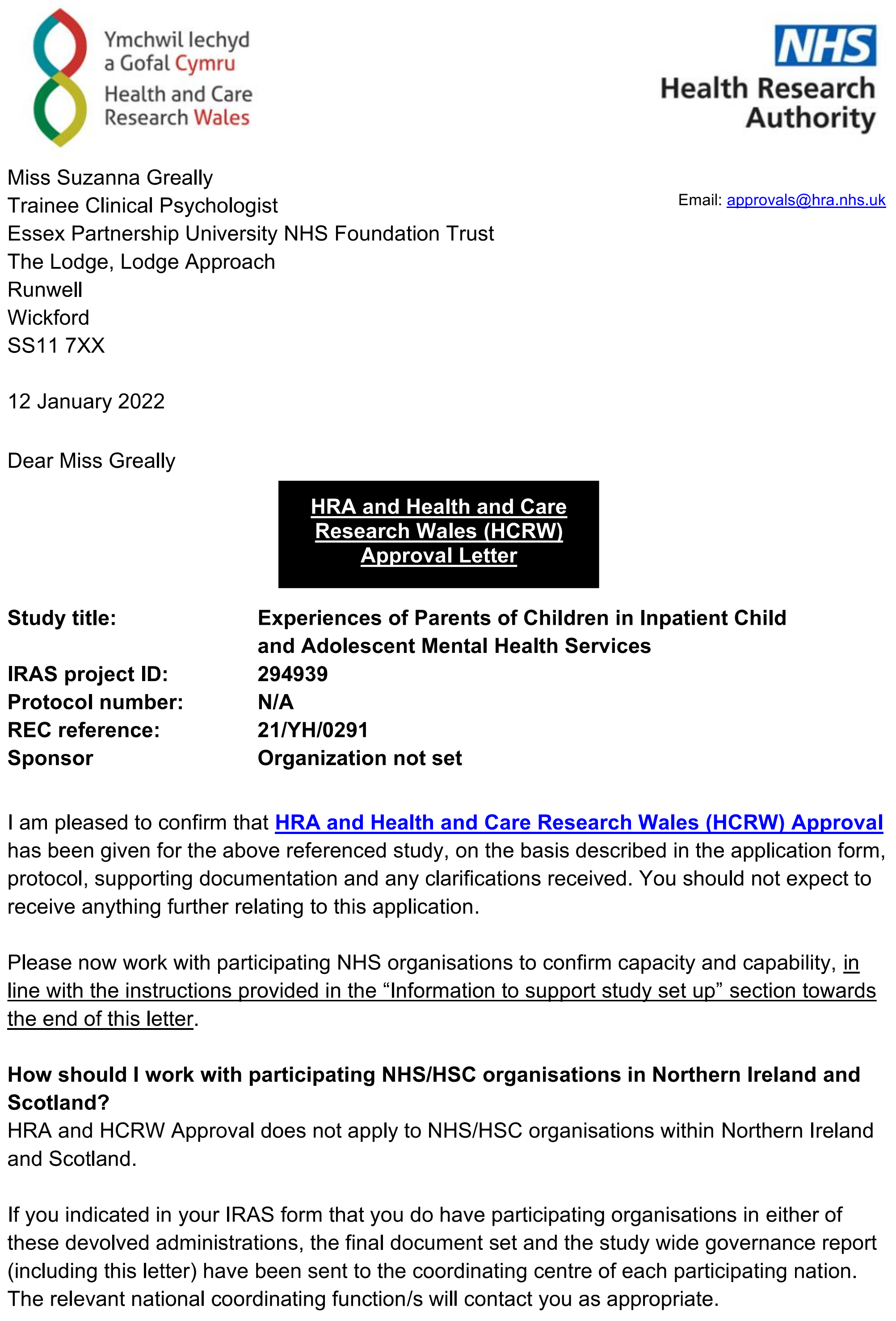
Appendix I

Transcription Key (adapted from Poindexter, 2003)

CAPS	Speaker's vocal emphasis
?	Rising intonation
.	Falling intonation
!	Rising emphasis
–	Utterance broken off
=	Successive utterances with no gap
[Interviewer:]	Interviewer utterances
[…]	Details redacted by author
{ }	Author explanations
{pause}	Pause longer than a breath
¶ new line	Shift in subject

Appendix J

NHS Health Research Authority Ethical Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Miss Suzanna Greally
Trainee Clinical Psychologist
Essex Partnership University NHS Foundation Trust
The Lodge, Lodge Approach
Runwell
Wickford
SS11 7XX

Email: approvals@hra.nhs.uk

12 January 2022

Dear Miss Greally

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: **Experiences of Parents of Children in Inpatient Child and Adolescent Mental Health Services**
IRAS project ID: **294939**
Protocol number: **N/A**
REC reference: **21/YH/0291**
Sponsor **Organization not set**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the “Information to support study set up” section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **294939**. Please quote this on all correspondence.

Yours sincerely,
Alex Thorpe

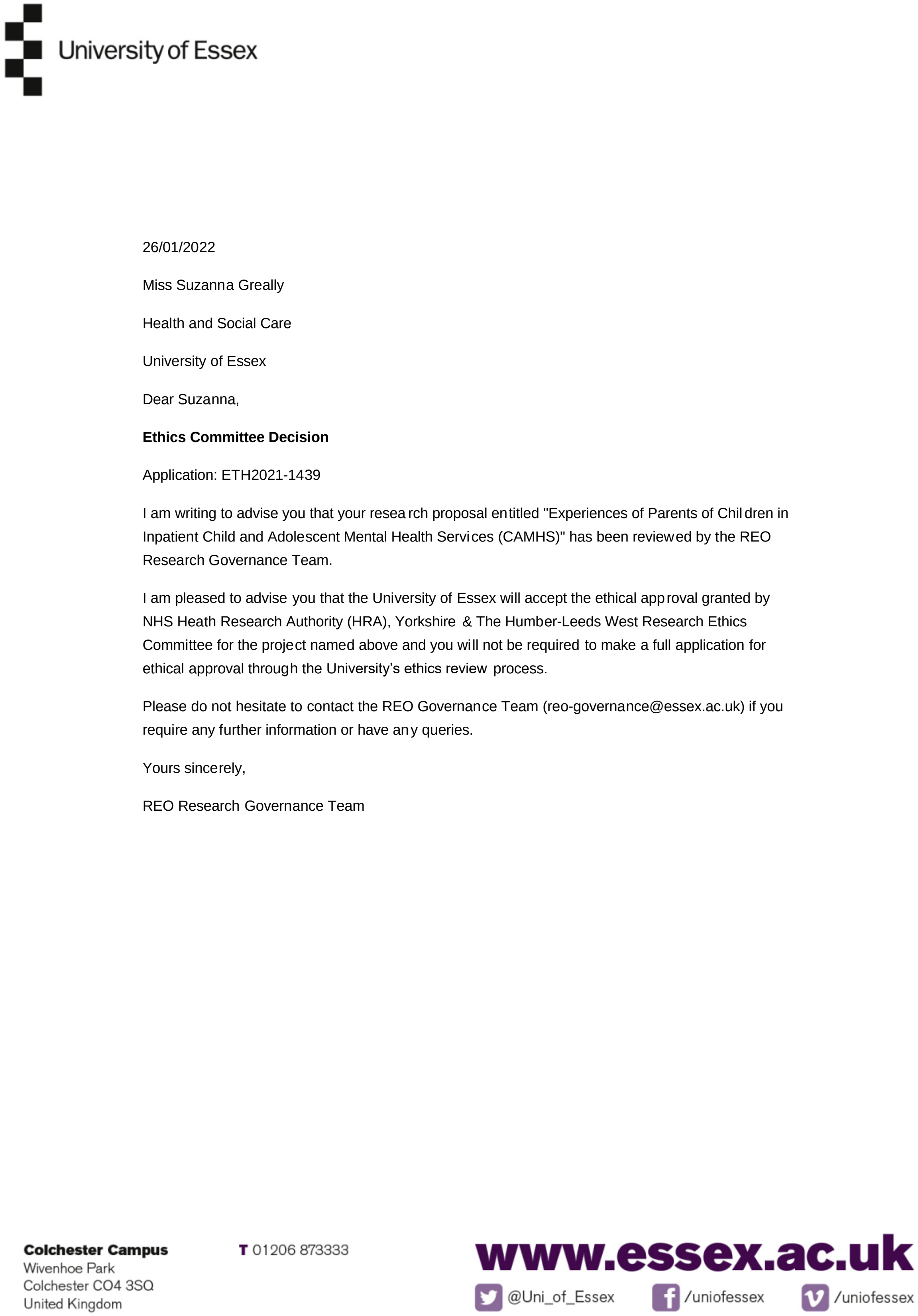
Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: *Ms Sarah Manning-Press, Sponsor's Represenative*

Appendix K

University Ethical Approval



University of Essex

26/01/2022

Miss Suzanna Greally

Health and Social Care

University of Essex

Dear Suzanna,

Ethics Committee Decision

Application: ETH2021-1439

I am writing to advise you that your research proposal entitled "Experiences of Parents of Children in Inpatient Child and Adolescent Mental Health Services (CAMHS)" has been reviewed by the REO Research Governance Team.

I am pleased to advise you that the University of Essex will accept the ethical approval granted by NHS Heath Research Authority (HRA), Yorkshire & The Humber-Leeds West Research Ethics Committee for the project named above and you will not be required to make a full application for ethical approval through the University's ethics review process.

Please do not hesitate to contact the REO Governance Team (reo-governance@essex.ac.uk) if you require any further information or have any queries.

Yours sincerely,

REO Research Governance Team

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

T 01206 873333

www.essex.ac.uk

@Uni_of_Essex /uniofessex /uniofessex

Appendix L

Consent Form

University of Essex
School of Health and Social Care
Doctorate in Clinical Psychology

Colchester Campus
Wivenhoe Park
Colchester
Essex
CO4 3SQ

IRAS ID: 294939
Participant Identification Number:

CONSENT FORM

Title of Research: **Experiences of Parents of Children in Inpatient Child and Adolescent Mental Health Services**

Chief Investigator: **Suzanna Greally**

Please initial box

1. I confirm that I have read the information sheet dated 20/12/21 *(Version 2)* for the above study. I have had the opportunity to consider the information, ask questions and I have had these answered satisfactorily.

2. I understand that this research involves an interview, which will be recorded and transcribed, and that the recording and transcript will be stored securely and accessible only to the research team.

3. I understand that my participation is voluntary and that I am free to withdraw at any time during the interview without giving any reason, and the recording will be erased.

4. I understand that once the interview is finished, I will not be able to withdraw as the anonymised interview transcript will be included in the research.

5. I understand that this research is being completed in part fulfilment of a Doctorate in Clinical Psychology, and information collected, including the interview transcript, will be anonymised and included in the Doctoral thesis.

6. I understand that direct quotes from my interview may be included in the write-up of this research. I understand that it will not be possible to identify me, my child, or any other person, in the write-up or in any further dissemination of the research.

7. I understand that I can choose to be interviewed on my own or with my partner. I understand that if I choose to be interviewed with my partner, I will be sacrificing my anonymity to them.

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

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of Researcher	Date	Signature

Version 1, 07/10/21 IRAS ID: 294939