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Experiences of parenting a child with an anxiety disorder: a secondary analysis of qualitative data

By

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ABSTRACT

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EXPERIENCES OF PARENTING A CHILD WITH AN ANXIETY DISORDER: A SECONDARY ANALYSIS OF QUALITATIVE DATA

Georgina Evdoka-Burton

A significant number of children and adolescents experience mental health difficulties, yet most young people do not access professional support (Merikangas et al., 2011). A systematic review of the qualitative literature was conducted to understand what children and young people perceive to be the barriers and/or facilitators to accessing help for mental health problems. The findings indicate several factors are important to young people when experiencing mental health difficulties, including the important role parents play in supporting young people and accessing treatment when necessary. It is therefore essential that more focus is placed on understanding parents' experiences and supporting parents when their child has a mental health difficulty.

Anxiety disorders are one of the most prevalent mental health difficulties experienced by children (Green, McGinnity, Meltzer, Ford & Goodman, 2005). Qualitative approaches have been used to explore the experiences of parents who have children with mental health difficulties, however no published research to date focuses on parenting a child with an anxiety disorder. The aim of the current research is to explore the experience of parenting a child (aged 7-11 years) meeting diagnostic criteria for an anxiety disorder. Semi-structured interviews were conducted with 16 parents sampled from a community population. A secondary analysis of the data was conducted using thematic analysis (Braun & Clarke, 2006). Four main themes were developed: parents feel 'helpless' in the face of their child's anxiety disorder and describe the 'emotional and demanding' nature of their role. The 'hard work and effort' invested in understanding and managing their child's difficulties was also identified as a theme. Despite the demanding nature of parenting a child with an anxiety disorder, parents also described a sense of 'hopefulness and progression' about the future and social connection with others. Overall, the findings of this study indicate that there are significant difficulties involved with parenting a child with an anxiety disorder, which parents attempt to manage in a number of ways. The clinical implications of these findings are discussed.

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Academic Thesis: Declaration of Authorship

I, Georgina Evdoka-Burton, declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

Title of thesis

Experiences of parenting a child with an anxiety disorder: a secondary analysis of qualitative data.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission.

Signed: Georgina Evdoka-Burton

Date: 25.08.2017

Acknowledgements

I would like to thank my supervisors for all their advice and support throughout this project. I would also like to thank my husband and family for their continued patience and encouragement, which has been much needed, and endlessly valued.

Definitions and Abbreviations

ADHD	Attention deficit hyperactivity disorder
ADIS	Anxiety Disorder Interview Schedule
ADIS-C/P	Anxiety Disorder Interview Schedule – Parent and Child Interview
BPS	British Psychological Society
CAMHS	Child and Adolescent Mental Health Services
CSR	Clinical Severity Ratings
DSH	Deliberate Self Harm
DSM	Diagnostic Statistical Manual
ESRC	Economic and Social Research Council
F	Father
GP	General Practitioner
HBM	Health Belief Model
K	Number of studies
M	Mother
N	Number of participants
NHS	National Health Service
OCD	Obsessive-compulsive disorder
ODD	Oppositional Defiance Disorder
P	Participant
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SES	Socio-economic status
SCAS	Spence Child's Anxiety Scale
SCAS-C/P/T	Spence Child's Anxiety Scale – Child/Parent/Teacher version
SCID	Structured Clinical Interview for DSM Disorders
UK	United Kingdom
US	United States of America
USA	United States of America

Chapter 1: Literature review

Children and adolescents' perceptions of the facilitators and barriers to seeking professional help for mental distress: a systematic review of the qualitative literature.

1.1 Introduction

1.1.1 Conceptualising mental health difficulties

There is much debate about how best to describe and understand mental health difficulties, with no clear concept of what constitutes mental health or ill-health and no clear distinction between abnormal and normal mental functioning (see for example Bolton, 2008). In an attempt to classify and categorise psychological experience, two main classification systems are currently used in psychiatry: the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) and the International Classification of Diseases: Classification of Mental and Behavioural Disorders (ICD-10). This has facilitated the development of evidence-based practice and National Institute for Health and Care Excellence (NICE) guidelines. These systems have been criticised, however, for applying scientific and medical models to thoughts, feelings and behaviours and for neglecting context. The use of diagnostic and medical language is also considered to be problematic in psychological services (British Psychological Society, BPS, 2013; 2015). For the purposes of this paper the term 'mental health difficulties' has been conceptualised as 'conditions which affect a person's mood, thinking and behaviour to such a degree that they have a significant effect on their ability to function as they would like to within different areas of their lives' (BPS, 2015).

Mental health disorders are one of the leading causes of disability worldwide (World Health Organisation, 2002), with lifetime prevalence rates estimated to be as high as 33% in the general population (Kessler et al., 2005a). Most mental health difficulties experienced by adults begin in childhood and adolescence, with half of all life-long serious mental health problems originating by age 14 years, and three-quarters by age 18 years (Murphy & Fonagy, 2012). A significant number of children and adolescents experience mental health difficulties. Epidemiological studies suggest that at any time point at least one in ten young people in the UK will have a diagnosable mental health problem (Green, McGinnity, Meltzer, Ford & Goodman, 2005). A recent meta-analysis indicates that the worldwide pooled prevalence of mental health difficulties in children and adolescents was 13.4% (Polanczyk, Salum, Sugaya, Caye & Rohde, 2015).

1.1.2 Implications of having a mental health difficulty and the importance of early intervention

Childhood and adolescence is a critical period of development. During this stage of life individuals start to separate from their parents, increase their independence and develop social relationships outside of the family (Steinberg & Silk, 2002). Mental health difficulties during this stage of development are likely to have long-term repercussions. Mental health difficulties in young people have been found to be associated with a number of adverse outcomes, including: academic under-achievement (Woodward & Fergusson, 2001), substance misuse (Hermens et al., 2013; Woodward & Fergusson, 2001), suicidality (Pelkonen & Marttunen, 2003), sexual risk-taking (Lehrer, Shrier, Gortmaker, & Buka, 2006), anti-social behaviour (Copeland, Miller-Johnson, Keeler, Angold, & Costello, 2007) and reduced life-satisfaction (Layard, Clark, Cornaglia, Powdthavee & Vernoit, 2014).

Early detection and treatment may reduce the severity and persistence of mental health problems and prevent the onset of associated co-morbidities (Ginsberg et al., 2014; Kessler et al, 2007; Wolk, Kendall & Beidas, 2015). Delays in treatment have been associated with adverse outcomes in psychosis, bi-polar disorder, major depressive and anxiety disorders (Boonstra et al., 2012). Early intervention is therefore essential.

1.1.3 Mental health treatment gap

Recent research has established the efficacy of using psychological interventions to treat children and adolescents with a wide range of presentations, including anxiety disorders, depression, and conduct disorder (James, James, Cowdrey, Soler, & Choke, 2015; Manassis, Russell, & Newton, 2010; Weisz, McCarty, & Valeri, 2006). Despite the evidence base and recommendations, it is well established worldwide there is a ‘treatment gap’ between the number of individuals experiencing mental health difficulties and those receiving treatment (Kohn, Saxena, Levav, & Saraceno, 2004).

The size of this treatment gap varies by location and presenting issue. In the UK it is suggested that up to 70% of young people who develop mental health difficulties will not receive timely or appropriate intervention (Children’s Society, 2008). The US national co-morbidity study for adolescents (Merikangas et al., 2011) found that less than one in five adolescents with anxiety, eating disorders or substance misuse received input from mental health services. Service intervention was higher for more severe difficulties and for externalised behaviours, but the overall estimate of adolescents in need of receiving mental health services was approximately one third (36%). This treatment gap is likely to be exacerbated for adolescent males (Rickwood, Mazzer, & Telford, 2015) and for ethnic minority groups (Flink, Beirens, Butte, & Raat, 2014).

Concern about this treatment gap has prompted the UK government to invest £143m to improve child and adolescent mental health services (CAMHS), with a focus on improving access to effective support for young people experiencing difficulties with their mental health (Department of Health, 2015).

1.1.4 Reluctance to seek help

Research suggests an important reason for this treatment gap is that children and adolescents are reluctant to seek professional help for mental health difficulties (de Girolamo, Dagani, Purcell, Cocchi, & McGorry, 2012; Rickwood, Deane & Wilson, 2007; Zwaanswijk, van der Ende, Verhaak, Bensing, & Verhulst, 2003), preferring to receive support from informal social networks (Rickwood et al., 2007) and increasingly through online resources (Rickwood et al., 2015).

Attempts to understand the treatment gap has led to two main areas of research: (1) factors that predict mental health service use, and (2) help-seeking behaviour, including the barriers and facilitators to service use.

1.1.5 Predictors of mental health service use

Research investigating predictors of mental health service use has mainly focused on the characteristics of individuals and families who access services. These studies indicate that young people with more severe mental health difficulties are more likely to access services (Merikangas et al., 2011), especially when these difficulties have an impact on friends, family and professionals in contact with that young person (Ford, Hamilton, Meltzer, & Goodman, 2008). Being Caucasian (Chavira, Stein, Bailey & Stein, 2004; Kataoka, Zhang & Wells, 2002), living in an urban location (Cohen & Hesselbart, 1993), and, in the USA, having insurance coverage (Angold et al., 2002; Zwaanswijk et al., 2003) also increase the likelihood of a young person accessing treatment.

This body of research provides an insight into the characteristics of individuals and families who access services but provides little information about the reasons *why* children and adolescents may be reluctant to seek help, or factors that might make it easier to seek help.

1.1.6 Help-seeking behaviour

Several theories and models have been proposed to conceptualise help-seeking behaviour, although none are widely accepted or routinely operationalised in the research exploring help-seeking for mental health difficulties (Gulliver, Griffiths, Christensen, & Brewer, 2012).

The Health Belief Model (HBM, Rosenstock, 1966; 1974) is one of the most widely utilised frameworks for understanding health-related behaviours and has been applied to help-seeking for mental health difficulties in the general population (see for example, Henshaw et al, 2009). This model proposes that an individual's decision to seek help from a mental health professional depends on the appraisal of the following three factors: first, perceived threat and severity of illness (i.e., the individual's perception of whether they have / may develop a mental health problem and the potential severity / consequences of having a mental health problem); second, the perceived benefits of seeking help (i.e. that treatment would reduce the severity or consequences of the problem) and third, the perceived barriers to seeking help (e.g. an individual may believe that problems should be solved without help from professionals or may fear that seeking help will lead to stigmatisation).

It is widely recognised that the HBM provides a thorough framework for understanding the factors that influence health-related behaviours. Although not specifically developed to understand help-seeking for mental health difficulties, the HBM has been influential in guiding research to explore the barriers and facilitators to accessing services for mental health difficulties (see for example, Henshaw & Freedman-Doan, 2009). It therefore provides a useful starting point from which to consider the barriers to accessing mental health services for children and adolescents. The model is limited, however, as it assumes a rational decision-making process and does not address the emotional aspects that may influence actual behaviour (Ajzen, 2005). In addition, little account of the social context of decision-making and the important role influential others, such as family and friends, have in the help-seeking process (for example, Andersen, 1995; Pescosolido, 1992). This is likely to be especially important when considering the help-seeking behaviour of children and adolescents.

Biddle and colleagues (2007) emphasise that help-seeking is a process embedded within socio-cultural context and propose a ‘cycle of avoidance’ to better understand ‘non-help-seeking’ for mental health difficulties in young people. Central to this theory is the proposal that the negative social meanings attributed to illness and being helped lead to the use of strategies to normalise and cope with distress, constantly renegotiating the threshold of when help is ‘needed’ (thus facilitating avoidance).

1.1.7 Barriers & facilitators to service use

A large body of research has focused on understanding the factors that prevent or facilitate children and adolescents seeking help. The first available systematic review of the research explored what young people themselves perceive to be the barriers and facilitators to accessing mental health services (Gulliver et al., 2010). Several barrier themes were identified across primary studies. The most prominent barrier themes included: perceived stigma, confidentiality and trust, difficulty identifying the symptoms of mental illness, concern about the characteristics of the provider, and self-reliance. Gulliver et al. (2010) emphasised the lack of research exploring factors that facilitate help-seeking, but their review suggests the importance of positive past experiences, social support and encouragement from others, confidentiality and trust, and positive relationships with service staff. Their findings reflect those suggested by earlier (non-systematic) reviews of the help-seeking literature (Rickwood, Deane, Wilson & Ciarrochi, 2005; Rickwood et al., 2007; Barker, 2007).

While the review by Gulliver et al. (2010) provides insight into the perceptions of young people, the age range of participants extended up to 25 years old and did not include children under 12 years old. In addition, most studies included in the review drew their participant pool from the general population with no assessment of mental health status, and with a limited number of participants with a (self-reported) mental health issue.

In a recent systematic review focusing on parents’ perceptions of the barriers and facilitators to accessing psychological treatment for mental health problems in children and adolescents (Reardon et al., 2017a), four key themes emerged: systemic/structural issues, views and attitudes towards treatment, knowledge and understanding of mental health problems and the help-seeking process, and family circumstances. It is interesting to note the emphasis on structural issues, which was not identified as a key theme by Gulliver et al. (2010) in their review which focused exclusively on adolescents and young adults. Reardon et al. (2017a) emphasise the limitations of existing questionnaire measures, finding that qualitative data provided information about barriers and facilitators not previously accounted for by quantitative measures (for example, the dismissiveness/supportiveness of professionals).

1.1.8 Rationale for the current review

There has been a growing awareness about the importance of listening to the perspectives of children and adolescents, especially regarding health and social care. Key government policies, such as National Service Framework for Children, Young People, and Maternity Services (Department of Health, 2004) have emphasised this approach and research has started to focus on actively involving and listening to children and young people when planning, improving and evaluating services (McAndrew & Warne, 2014).

The most recent systematic review of young people’s own perspectives of barriers and facilitators to seeking help was completed in 2010 (Gulliver et al., 2010), and was the first review to include qualitative as well as quantitative data. There had previously been a much stronger focus on quantitative data, looking at factors that predict service use (Merikangas et al., 2011) and associations between measured barriers and intention to seek help (Ciarrochi, Wilson, Deane, & Rickwood, 2003).

Previous reviews, including Gulliver et al. (2010), have included a wide age range of ‘young people’, spanning from early adolescence to young adulthood (12-25 years). Barriers and facilitators are likely to change significantly during this period, for example a recent study found that mental health help-seeking in children and younger adolescents is qualitatively different to help-seeking in older adolescents and young adults (Rickwood et al., 2015).

1.1.9 Review aims

The purpose of this study, therefore, is to provide an up-to-date systematic review of the qualitative literature reporting what children and young people themselves perceive to be the barriers and/or facilitators to seeking help for mental health problems. This review is specifically focused on accessing help for mental health. Previous reviews have given limited attention to qualitative studies, this review will address this gap. Departing from previous reviews, this review focuses on children and adolescents up to the age of 18 years only, which is in line with most child and adolescent mental health services (CAMHS) within the UK. The review was conducted following PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009).

1.2 Method

1.2.1 Literature search

This systematic literature review builds on a recent systematic review (Reardon et al, 2017a), which focuses on parents' perceived barriers and facilitators to accessing psychological treatment for mental health problems in children and adolescents. The current review set out to extend the above review, focusing on young people's perspectives rather than parents' perspectives. The initial search strategy and preliminary inclusion and exclusion criteria match the above review and were kept deliberately wide to ensure that papers referencing parents *and* young people's perspectives would be returned in the initial searches.

The original search was conducted in October 2014 (Reardon et al., 2017a) and was replicated using the same strategy in October 2016 in the current review. Consistent with Reardon et al. (2017a) the NHS Evidence Healthcare database was used to run a combined search of Medline, Psychinfo and Embase. The Web of Science Core Collection was searched separately. These databases were selected as they collate information for health and social care professionals and include a range of publications and literature in social science, health and medicine, psychology and psychiatry. These four databases were chosen to provide research that is multi-disciplinary and cover different subjects, geographic areas and different time periods, therefore making the literature search more inclusive.

The search terms developed by Reardon et al. (2017a) were used in the current review, relating to four overarching concepts (see Appendix A1 for full search terms): barriers/facilitators; help seeking; mental health; parents/children/adolescents. Keywords for each of these concepts were generated by Reardon et al. (2017a), based on relevant literature and previous reviews. Search terms within each concept were combined using 'AND' to search for titles and abstracts. The search was limited to articles published in English. Hand search methods were also used by checking the reference list of articles included at the full text screening stage.

1.2.2 Eligibility criteria

Criteria for study inclusion

To be included in the literature review studies were required to meet the following criteria, based on those developed by Reardon and colleagues (2017a), and adapted for the current study:

i. Participants were children and adolescents up to and including the age of 18 years. Studies were excluded if the mean age of participants was over 18 years, or if the sample included participants over the age of 21 years.
ii. Study reported children's and/or adolescents' perceived barriers or facilitators to accessing psychological treatment for mental health problems. Studies reporting only parental perspectives of barriers/facilitators were excluded.
iii. Study published in English in a peer reviewed journal.

It was decided to include perspectives about a broad range of mental health difficulties, and so studies focusing on general mental health or emotional and behavioural difficulties were included, as well as those exploring specific diagnostic categories, such as Depression or ADHD.

The term 'psychological treatment' is operationalised as meaning treatment obtained from professionals working in school settings, primary care or specialist mental health services. Psychological strategies to manage mental distress, such as talking therapy, are included; studies that focused exclusively on other types of treatment, such as medication, were not included in this review. In addition, the focus of this review is on barriers and facilitators to *initial access* to treatment, rather than ongoing treatment.

Criteria for study exclusion

This review is specifically concerned with the views and beliefs held by children and adolescents about help-seeking; studies focusing exclusively on factors that predict, or were statistically associated with, help-seeking were therefore excluded. In addition, this review focuses on perceptions of accessing psychological treatment within the general population; studies focusing on children and adolescents who may not have access to the same help-seeking opportunities as the general population (such as young offenders or looked after children), and those focusing on accessing treatment for developmental difficulties and autistic spectrum disorders were also excluded from this review. The full exclusion criteria are outlined below:

i. Study did not report barriers or facilitators to accessing treatment for mental health problems in children/adolescents.
ii. Study was a review.
iii. Study was not published in a peer-reviewed journal.
iv. Study only reported parent perceived barriers or facilitators to accessing treatment for mental health problems.
v. Study only reported factors associated with or predictors of parent or child/adolescent help seeking behaviour / service use / help seeking intentions.
vi. Study only reported findings from an intervention designed to address one or more barrier to help-seeking.
vii. Study only reported barriers/facilitators to accessing ongoing to treatment, not initial access to treatment.
viii. Study only reported barriers/facilitators to accessing treatment for autism spectrum disorder or developmental disabilities.
ix. Participants in the study were not children or adolescents (excluded if the mean age of the children/adolescents was over 18 years or if the sample included adults over the age of 21 years).
x. Study did not report any qualitative or quantitative data that could be extracted.
xi. Study only reported barriers/facilitators to accessing medication or inpatient psychiatric care.
xii. Participants in the study represented a special population (i.e., children/adolescents with an intellectual or developmental disability, young offenders, children/adolescents with mental health problems in the context of a specific physical health condition, looked after children).

1.2.3 Qualitative studies

Qualitative and quantitative studies were initially included and screened during full text screening (as recommended by the Centre for Reviews and Dissemination, 2009). Once papers had been included based on the full inclusion and exclusion criteria, then all papers were screened again and studies that did not use qualitative methods of data collection and analysis, either as the main focus of the study or as a discrete part of a larger mixed-method study, were excluded from this review.

1.2.4 Data selection

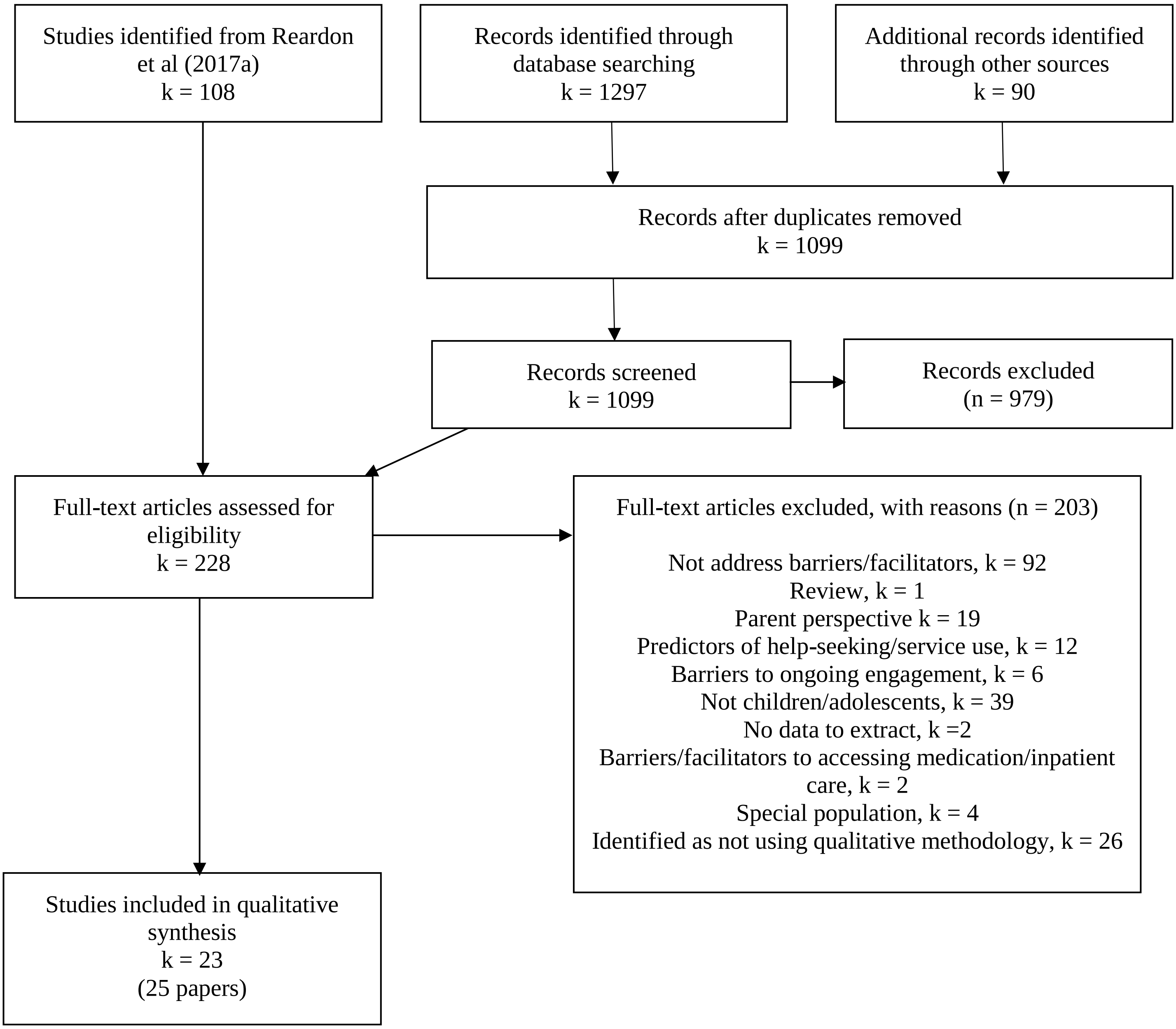
Studies included in the review were identified through the following process:

1. Studies pre-dating October 2014 were identified using the abstracts extracted by Reardon et al. (2017a) during their search process. During abstract and full text screening, Reardon et al. (2017a) identified studies where participants included only adolescents (excluded from their review on this basis). These papers were therefore included as studies for potential inclusion in this study and were automatically taken to full-text screening. All papers included by Reardon et al. (2017a) after full text screening were also screened at full-text stage for inclusion in this review, as they potentially included adolescent as well as parent perspectives.
2. An updated search was conducted (October 2014 – October 2016) replicating the search strategy used by Reardon et al. (2017a), with the alteration that studies focusing on child and adolescent perspectives were included and studies focusing only on parent perspectives were excluded.

The total number of papers identified through Reardon et al. (2017a) was 108, and these were screened by GEB and another member of the research team (PL) at full-paper screening stage to establish eligibility for this review.

In total 1297 papers published since 2014 were retrieved through the combined electronic database search, leaving 1064 records after duplicates were removed. Hand searching identified 90 further potentially eligible papers. Two reviewers (GEB and PL) both screened 1099 titles and abstracts independently and identified articles for inclusion or exclusion using the criteria outlined above. The full paper was sourced if either reviewer identified the study for potential inclusion. A total of 228 full papers were independently assessed by the same two reviewers for inclusion in the study; agreement between reviewers was good (95%). Any papers meeting the exclusion criteria were coded by the primary reason for exclusion. Discrepancies were passed on to a third member of the research team (CC) for a final decision. In total 25 articles (23 studies) met criteria for inclusion in this review. Figure 1 summarises this process.

Figure 1. *Flowchart of study selection and search results.*



1.2.5 Data extraction

Data extraction from included studies was undertaken by the primary author (GEB) using a data extraction tool developed by Reardon et al. (2017a), adapted for this qualitative review and refined after initial piloting. The data extracted from each study included the following information: (a) design features, including methodology used (qualitative or mixed methods), study location (e.g. USA, UK) and setting (e.g. school, mental health clinic); (b) sample characteristics, including participant numbers, gender, age range, mental health status and type of mental health problem, mental health service use and whether the study targeted a particular ethnic group or urban/rural population; (c) the method of data collection (i.e. focus group, interviews or both) and areas of relevant questioning, and (d) key findings relating to perceived barriers and facilitators extracted from the results section, including author comments supported by participant quotes, participant quotes without author comments, and author comments without participant quotes.

Differing views exist about what constitutes data for systematic reviews of qualitative research (Thomas & Harden, 2008). Noyes and Lewin (2011) summarise these views into two approaches for classification of 'evidence': one is to consider that all primary qualitative data must be supported by quotations from participants; the other is that any data presented in a primary study of relevance to the review question, irrespective of availability of a supporting participant quotation, can be included in a review. The latter approach was used in the current review, with 'data' conceptualised as participant quotations *and* the interpretations and summaries relating to barriers and facilitators to help-seeking as reported in the results section.

1.2.6 Quality rating

The critical appraisal of qualitative research is a contested area with some arguing that it is not appropriate to assess qualitative research, and concern that a common set of principles be applied to a wide range of qualitative epistemological and methodological approaches (Dixon-Woods, Shaw, Agarwal, & Smith, 2004; Mays & Pope, 2000). It has however become widely accepted and expected that quality be assessed in qualitative research, particularly when reviewing a body of literature and making recommendations (Centre for Reviews and Dissemination, 2009; Noyes & Lewin, 2011; Thomas & Harden, 2008). Despite concerns about the limitations of using standardised criteria to assess quality, it is appropriate and responsible to critically appraise qualitative research. It is important for guidelines to be flexible and to acknowledge the limitations of this approach, but critical appraisal is necessary to facilitate the contribution of qualitative research to scientific advancement, and to ensure that wider organisations and researchers recognise this contribution.

There is no consensus about how to assess quality in qualitative research, and a wide variety of appraisal tools exist. The quality of studies included in this review were assessed using a modified version of the criteria developed by Kmet, Lee and Cook (2004) for use with qualitative studies. In line with Reardon et al.'s (2017a) approach to quality assessment, the checklist developed by Kmet et al. (2004) was modified using Dixon-Woods' (Dixon-Woods, Shaw, Agarwal & Smith, 2004) prompts for appraising qualitative research. In acknowledgement that qualitative methodology is not suited to some research objectives, the question ‘Are the research questions suited to qualitative enquiry?’ was added to the quality criteria. Two questions relating to (1) the study’s connection to a theoretical framework and (2) the use of reflexivity were removed from the criteria set out by Kmet et al. (2004), in acknowledgement that these objectives are only appropriate for some methods of qualitative enquiry, and do not necessarily indicate quality.

The nine items on the checklist are rated using a three-point scale (yes=2, partial=1, no=0), with a maximum score of 18 (see Appendix A3). Items on the checklist related to methods of data collection, analysis and whether the conclusions were supported by the results, were considered specifically in relation to the part of the study that focused on perceived barriers and facilitators. See Appendix A4 for the completed quality assessment scores for included studies. Based on the final score, studies were classified as low (0-11), medium (12-15) and high (16-18) quality. This classification was based on the spread of the scores and is in line with the approach used by Reardon et al. (2017a), to allow comparison between the reviews.

The quality of each included research paper was assessed by the primary author (GEB) using this approach. It was decided not to exclude studies from the review based on quality assessment, as studies of low quality may still offer valuable information (Barnett-Page & Thomas, 2009).

1.2.7 Data synthesis strategy

Thematic synthesis (Thomas & Harden, 2008) was used to aggregate the findings. This approach is identified as one of a number of techniques described in ‘ESRC Guidance on Conducting Narrative Synthesis’ (Popay et al., 2006). Three stages were used to synthesise data from primary studies, these stages are outlined in Table 1.

Table 1. *Data synthesis stages.*

Stage	Description
1. Initial coding	All participant quotations and interpretations/summaries by the study authors relating to barriers and facilitators to help-seeking and reported in the results section, was tabulated in an Excel spreadsheet. Each line of text was initially coded according to its meaning. The use of line by line coding facilitated the 'translation' of concepts from one study to another, a key aspect of synthesising qualitative research (Thomas & Harden, 2008). During this stage of synthesis, all text was analysed to ensure that a code had been given where appropriate.
2. An iterative process was used to refine and organise these initial codes into related areas, to construct 'descriptive' themes.	During this process, similarities and differences across initial codes were considered, and initial codes were grouped together where meaningful. New 'descriptive' themes were created at this stage to capture the meaning of a group of initial codes. This process was conducted separately for facilitator and barrier codes.
3. The development of 'analytic' themes	This stage involved further refining the descriptive themes to create over-arching barrier/facilitator themes, involving an interpretation of the underlying reason why children and adolescents discussed this as a barrier/facilitator to help-seeking. The number of studies endorsing each theme was recorded and themes then ranked according to their prevalence across included papers.

The synthesis was undertaken by one reviewer (GEB), with research supervisors checking data extraction and themes for consistency and credible interpretation. The overarching themes and corresponding descriptive and initial codes relating to these themes can be seen in Appendix A5. In total, this process resulted in the generation of ten analytical themes; five related to barriers and five related to facilitators of help-seeking for mental health problems in children and adolescents.

1.3 Data Extraction

1.3.1 Study characteristics

Twenty-three studies used a qualitative methodology to explore child and/or adolescent perspectives about the factors that make it easier or more difficult to seek help for mental health difficulties and were therefore included in this review. Two of these studies each had two published papers reporting different aspects of the results (Fortune, Sinclair, & Hawton, 2008a, 2008b; Lindsey, Joe, & Nebbitt, 2010; Lindsey et al., 2006) and thus 25 research papers were analysed in total. Table 2 summarises the characteristics of included studies. A wide variety of studies were included in the review.

1.3.2 Year, location and setting of studies

The included studies were published between 2001 and 2016. The majority of studies were conducted in the USA (n = 12), the UK (n = 5) and Australia (n = 3), with one study from each of New Zealand, Canada and Portugal. Most studies selected participants from urban and suburban populations, with only one study focusing specifically on adolescents living in a rural area in Australia (Francis, Boyd, Aisbett, Newnham & Newnham, 2006). Over half of the studies were conducted in mainstream school settings (n=13), with one study focusing on adolescents in alternative school provision and two studies recruited participants from a school and community/clinical populations (De Anstiss & Ziaian, 2010; Wisdom, Clarke & Green, 2006). Two studies utilised a community sample, with four studies specifically recruiting participants from clinical or at-risk populations. One study did not specify recruitment or sampling procedures.

1.3.3 Methodologies employed

Qualitative interview and focus group methods were used in 21 studies, using either one or a mixture of these methods. Two studies (Bussing et al., 2012; Fortune et al., 2008a, 2008b), employed a survey method and used qualitative analysis to explore participants’ responses to open-ended survey questions. There is a large discrepancy in sample size between included studies, which ranges from 6 to 2,954 participants; the two studies using a survey method (Bussing et al., 2012; Fortune et al., 2008a, 2008b) had much larger sample sizes (see Table 2).

1.3.4 Participant characteristics

Many studies reported the age range of participants, although two reported the school year/grade only. Most studies focused on participants aged 11 years and above (n=22); with only one study including participants under this age, with an age range from 7 to 18 years (Del Mauro & Jackson Williams, 2013). Most studies have samples of mixed gender (n = 13); two studies focus exclusively on male adolescents' experiences of help-seeking (Lindsey et al., 2006, 2010; Timlin-Scalera, Ponterotto, Blumberg & Jackson, 2003); three studies did not report the gender of participants. The ethnicity of participants was not reported in six research papers; eight studies were comprised of a majority of white/Caucasian participants. Four studies focused exclusively on African American groups of adolescents; one study focused on Mexican American adolescents, and four studies sampled specifically to increase ethnic diversity.

Table 2. *Characteristics of included studies.*

Study	**N**	**Age range (years)**	**Country**	**Study setting**	**% Female Ethnicity Urban/rural**	**Mental health status**	**Mental health service use**	**Method of data collection (focused specifically on perceived barriers/facilitators)**	**Quality rating score (0-18)**
Becker, Swenson, Esposito-Smythers, Cataldo, & Spirito, 2014	13	12-17	USA	Community sample; adolescents with at least one parent enlisted in the military; recruited through outreach and support programs for military families.	Female (38%) Majority Caucasian	Adolescents included regardless of mental health status or service use.	Adolescents included regardless of mental health status or service use.	Semi-structured interviews & focus groups; address barriers to engaging in mental health treatment among military adolescents; also asks about desirable service elements.	16 (high)
Breland-Noble, Wong, Childers, Hankerson, & Sotomayor, 2015	28	11-17	USA	Secondary analysis of data collected from clinical intervention for depression development study.	Black African American (100%)	Not reported.	Not reported.	Interview & focus group; address experiences of religious and spiritual coping when dealing with depression and the interplay with depression treatment.	12 (medium)
Bullock, Nadeau, & Renaud, 2012	15	14-18	Canada	Participants recruited through a ‘Depressive Disorders Program’ at a psychiatric hospital.	Female (87%)	All participants had made at least one suicide attempt within previous two years.	All referred to Depressive Disorders Program at psychiatric hospital; 50% of sample met criteria for depressive disorder; 33% met criteria for cluster B personality disorder (SCID II).	Semi-structured interview; address the role of spirituality/religion in mental health service utilization, attitudes and willingness to use mental health services in the year before a suicide attempt.	15 (medium)

Study	N	Age range (years)	Country	Study setting	% Female Ethnicity Urban/rural	Mental health status	Mental health service use	Method of data collection (focused specifically on perceived barriers/facilitators)	Quality rating score (0-18)
Bussing et al., 2012	148	14-19	USA	Longitudinal study assessing ADHD detection and service use School screening	Female (59%)	Focus on adolescents at high or low risk of ADHD 75% high risk; 25% low risk	Previous ADHD treatment (58%)	Open ended question included on 'treatment perception' survey: 'What other undesirable effects are you concerned about?"	16 (high)
Chandra & Minkovitz, 2007	57	8th grade (age not specified)	USA	Two public middle schools	Female (74%) African American (30%) Suburban		Purposive sampling for mental health service use: 39% had sought help from school counsellor; 11% had experiences with mental health services outside of school	In-depth interviews; explored teen attitudes towards seeking mental health services and the factors that influence these views	17 (high)
De Anstiss & Ziaian, 2010	85	13-17	Australia	Community; recruited from multicultural and refugee/migrant organisations, schools, community services.	Female (48%) All participants were refugees of mixed ethnic backgrounds	Not reported	Not reported	13 semi-structured focus groups, addresses actual and perceived barriers to services; questions explore the meaning of mental health/illness, coping, help-seeking and barriers to help-seeking.	15 (medium)
Del Mauro & Jackson Williams, 2013	31	7-18	USA	Community population, convenience sampling including neighbourhood	Female (71%) Majority Caucasian middle/upper		Non-clinical population, but 19% had previously attended a therapy session	9 focus groups; questions related to knowledge about mental illness, therapy process, attitudes towards therapy, openness about mental illness, towards other	16 (high)

Study	**N**	**Age range (years)**	**Country**	**Study setting**	**% Female Ethnicity Urban/rural**	**Mental health status**	**Mental health service use**	**Method of data collection (focused specifically on perceived barriers/facilitators)**	**Quality rating score (0-18)**
				listservs, word of mouth	class Suburban			people who utilize professional counselling services and about themselves utilizing professional psychological help	
Fleming, Dixon, & Merry, 2012	39	13-16	New Zealand	Schools for alternative education (young people alienated from mainstream education)	Female (26%)	Not reported	Not reported	8 semi-structured focus groups. Focus on depression, questions explore understanding, coping and seeking help for depression	15 (medium)
Fornos et al., 2005	65	13-18	USA	School - middle and high school students	89% of school population Mexican American	Not reported	Not reported	9 semi-structured, open-ended focus groups; addresses adolescents' knowledge and attitudes about depression and treatment for depression; explores acceptability of school based intervention to use peer facilitators to increase help-seeking	11 (medium)
Fortune et al., 2008a, 2008b	*a*. 332 *b*. 412 *c*. 2,954	15-16	UK, England	41 representative secondary schools taking part in a large self-report anonymous survey about self-harm	*c*. Female (54%) White (82%)	*a & b*. current or previous self-harm *c*. All participants asked to respond regardless of	Not reported	Open ended responses to written survey questions related to barriers to seeking help before an episode of DSH barriers to seeking help after an episode of DSH	14 (medium)

Study	N	Age range (years)	Country	Study setting	% Female Ethnicity Urban/rural	Mental health status	Mental health service use	Method of data collection (focused specifically on perceived barriers/facilitators)	Quality rating score (0-18)
						personal history of self-harm		what can be done to help prevent young people from harming themselves	
Francis, Boyd, Aisbett, Newnham, & Newnham, 2006	52	Year 9 & 10	Australia	4 rural secondary schools	Female (71%) Rural population	Not reported	Not reported	8 focus groups; scenarios representing common mental health problems; questions exploring help-seeking behaviour and perceived barriers to seeking help in relation to the scenarios	16 (high)
Goncalves & Moleiro, 2012	16	12-17	Portugal	Public schools from areas with moderate to high representation of immigrant families	Female (31%) All participants from migrant and ethnic minority backgrounds	Not reported	31% had previously visited psychologist	3 focus groups; explore perspectives about access to mental health care for migrant and ethnic minority families. The following areas are included in interview topic guide: concepts of mental health, barriers and facilitators to help seeking and access to mental health care	12 (medium)
Huggins et al., 2016	6	18	USA	3 high schools; 2 public/1 private	No demographic details were collected Rural & urban schools	Not reported	Students were recruited based on principal knowledge that they were the most closely affiliated with high school mental health services	Semi-structured interviews; focus on mental health, stigma, and recommendations for reducing stigma and improving effectiveness of school mental health services.	15 (medium)
Kendal, Keeley, & Callery, 2014	23	11-16	UK, England	Three UK high schools where a high school-based	Female (65%)	Not reported	39% had used a mental health project developed in school	Interviews; focus on high school-based emotional support project; questions	16 (high)

Study	**N**	**Age range (years)**	**Country**	**Study setting**	**% Female Ethnicity Urban/rural**	**Mental health status**	**Mental health service use**	**Method of data collection (focused specifically on perceived barriers/facilitators)**	**Quality rating score (0-18)**
				emotional support project had been implemented	urban			explore useful support, the importance of confidentiality, help-seeking and barriers and facilitators to help seeking	
Klineberg, Kelly, Stansfeld, & Bhui, 2013	30	15-16	UK, England	4 schools in areas of high ethnic diversity, Year 11 pupils	Female (80%) Asian (40%) urban	Self-harm: 33% never; 30% one occasion; 37% repeatedly	Not reported	Qualitative individual interviews. Focus on self-harm: investigating views on coping with stress, self-harm and help-seeking	16 (high)
Michael A. Lindsey, Chambers, Pohle, Beall, & Lucksted, 2013	16	11-14	USA	Two elementary/middle schools	Female (50%) African American (100%) urban		Self-reported use of mental health services in last 6 months: 4 ‘need’ services; 5 received school-based services; 7 not received any	Focus groups; examine help-seeking behaviours and underlying factors related to formal mental health treatment and school mental health services	16 (high)
M. A. Lindsey et al., 2010; M. A. Lindsey et al., 2006	18	14-18	USA	Clinic: 10 participants recruited from mental health clinics; 8 recruited from community centres with high-risk of depression (violence prevention program, truancy abatement center, homeless shelter)	Females (0%) African American males	Elevated depressive symptom levels (Centers for Epidemiologic Studies Depression Scale); not diagnosed with clinical depression	10 participants receiving treatment for depressive symptoms	Qualitative interviews; focus on depression; interview questions explore symptom recognition, help-seeking and perceptions of mental health services	17(high)

Study	**N**	**Age range (years)**	**Country**	**Study setting**	**% Female Ethnicity Urban/rural**	**Mental health status**	**Mental health service use**	**Method of data collection (focused specifically on perceived barriers/facilitators)**	**Quality rating score (0-18)**
McAndrew & Warne, 2014	7	13-17	UK	Purposive sampling but not clear where participants recruited from	Female (100%) White British (100%)	All participants had experience of self-harm and/or suicidal behaviour	Not reported	Interviews; elicit the narratives of young people who engage in self-harm and suicidal behaviour, in order to identify what was helpful and/or unhelpful, and what their future needs might be from a diverse range of statutory and non-statutory services.	11 (medium)
Pailler et al., 2009	60	12-18	USA	Emergency Department, tertiary care children's hospital	Female (52%) African American (65%) urban	Psychiatric illness or history not part of inclusion or exclusion criteria	Not reported	Interviews; explores beliefs about the acceptability of universal depression screening in the ED and perceptions of the barriers and facilitators to a mental health referral after a positive depression screen in the ED	17 (high)
Prior, 2012	8	13-17	UK, Scotland	School with a new counselling service	Female (75%)	Not reported	All participants had successfully completed a course of counselling at school	In-depth semi-structured interviews; explores the key features and stages of the help-seeking process when accessing school counselling	14 (medium)
Timlin-Scalera, Ponterotto, Blumberg, & Jackson, 2003	26	14-18	USA	Public high school	Female (15%) White (100%) suburb	Not reported	Not reported	Semi-structured interviews; address help seeking from a mental health professional, barriers/facilitators to accessing services, perceptions of mental health professionals	16 (high)

Study	N	Age range (years)	Country	Study setting	% Female Ethnicity Urban/rural	Mental health status	Mental health service use	Method of data collection (focused specifically on perceived barriers/facilitators)	Quality rating score (0-18)
Wilson & Deane, 2001	23	14-17	Australia	High school in industrial area	Female (52%) Australians of European descent (91%)			4 focus groups; addresses help seeking behaviours, reducing barriers, raising sensitive issues and increasing appropriate engagement	16 (high)
Wisdom, Clarke, & Green, 2006	*a*. 10 *b*. 5 *c*. 7	*a & b*: 14-19 *c*: 15	USA	Mental health clinic (in treatment) Mental health clinic (not in treatment) Local high school	*a & b*: Female (60%) White (87%) *c*: Female (71%)	*a & b*: diagnosis of depressive disorder *c*. diagnosis not assessed	*a*. have received mental health treatment *b*. not in treatment *c*. focus group participants - not assessed/3 participants had received MH treatment	*a & b*: Interviews *c*: 1 focus group Interviews and focus group questions focus on understanding of depression, concerns about approaching professionals for help, the process of obtaining treatment, how the process can be improved.	15 (medium)

Note: ADHD = Attention deficit hyperactivity disorder; DSH = Deliberate Self Harm; n = number of participants; SCID = Structured Clinical Interview for DSM Disorders; USA = United States of America; UK = United Kingdom.

1.3.5 Mental health status of participants and mental health service use

Ten of the included studies did not use mental health status or experience of mental health service use to select participants for inclusion. Of these, two found that participants did have some experience of mental health service use (Del Mauro & Jackson Williams, 2013; Goncalves & Moleiro, 2012) but the experiences of these young people were not separately analysed in these studies.

A small number of studies focused specifically on adolescents' experiences of and attitudes towards self-harm and suicide (n=3) and all collected data about the prevalence of these behaviours, but did not report mental health service use. Five studies explored participants' experiences of mental health service use, such as school counselling programmes, and used purposive sampling to increase recruitment from those who had accessed these services. These studies did not collect data about or did not report the mental health status or diagnosis of participating adolescents.

Four studies specifically focused on adolescents with mental health difficulties and included some participants who had been referred to mental health services. Of these four studies, one focused on adolescents at high or low risk of ADHD and three focused on adolescents with depression, depressive symptoms or depressive disorders. Only one study included in the review used an exclusively clinical sample, where all adolescents had been referred to a treatment programme at a psychiatric hospital (Bullock et al., 2012). None of the included studies explicitly compared or focused on the differences between clinical and non-clinical populations.

1.3.6 Focus on barriers and facilitators

Twenty-two studies presented data relating to barriers to mental health service use; the only study containing no data relating to barriers focused exclusively on facilitating factors (Bullock et al., 2012). Most studies elicited themes about facilitators (n = 19) to accessing psychological treatment for mental health difficulties; four studies did not address facilitators, focusing on barriers to service use only (Becker et al., 2014; Bussing et al., 2012; Fleming et al., 2012; Francis et al., 2006). The amount of focus placed on barriers and/or facilitators to mental health services use varied; for some studies this was a primary aim of the research (for example, Becker et al., 2014; Wisdom et al., 2006); while for other studies this was one aspect in a wider area of research (for example, Bussing et al., 2012; Breland-Noble et al., 2015).

1.4 Results

1.4.1 Quality assessment

Quality was assessed using a modified version of the criteria developed by Kmet et al. (2004); ratings of the included studies are detailed in Table 2. All studies were rated as being of medium or high quality, with scores ranging from 11 to 17 (out of a possible 18). Most studies were rated to have well described and appropriate research objectives, study design and context, and all were rated as appropriate for qualitative research. Sampling strategy and methods of data collection tended to have limited description among studies not rated as high quality. Most studies lacked clarity about the method of analysis used and did not provide an 'audit trail' for readers to understand the interpretation of the results. A strength in most studies was the use of methods to increase the credibility of the findings, such as triangulation and inter-rater reliability, and the use of participants' quotations to contextualise the findings.

Studies were not excluded from the review based on quality assessment; studies of lower quality also provided valuable information (Barnett-Page & Thomas, 2009), with participant quotations and researcher interpretation included in the results. Assessment therefore provided an awareness of the overall quality of the research included in this systematic review, whilst also indicating areas in which the quality of qualitative research can be improved.

1.4.2 Data synthesis: Perceived barriers and facilitators

Thematic synthesis (Thomas & Harden, 2008) of the 25 papers led to the development of five over-arching themes relating to barriers to mental health service use and five over-arching facilitator themes. For the detailed findings of this thematic synthesis see Appendix A5. Table 3 summarises these over-arching themes in order of frequency of studies in which the theme was addressed; each theme is discussed in more detail below.

Table 3. *Key barrier and facilitator themes in order of frequency of studies that report data relating to the theme.*

Barrier themes	**Number of studies**
Concern about the negative consequences of seeking help	19
Psychological treatment is not wanted/not perceived to be needed	14
Lack of trust and confidence in mental health treatment and professionals	13
Limited understanding and awareness of mental health & services	9
Practical/logistical difficulties	6
Facilitator themes	
Trusting relationship with referrers and service providers	10
Social support and encouragement from others	9
Motivation to seek help	8
Information and awareness about mental health and related services	7
Accessibility of mental health services	2

Barrier Themes

Three main over-arching barrier themes were strongly represented in included studies: concerns about the consequences of seeking or accessing help; adolescents not wanting or believing they need psychological treatment, and a lack of trust and confidence in mental health services and professionals. Two further over-arching themes, although less frequently endorsed, were developed in the analysis: one relating to the lack of information known about mental health, and a theme related to practical difficulties preventing access to treatment.

1. Concerns about the consequences of seeking/accessing help

The main over-arching theme present in almost all qualitative studies (n=19) is the perceived threat associated with seeking help for mental health problems. Adolescents in a wide range of studies expressed fear and concern about the potential consequences of being labelled with a mental health problem.

Adolescents expressed concern about the stigma attached to mental health difficulties, and fear of being labelled as ‘crazy’ and ‘weak’ for seeking help. This theme was present in studies of different population groups across different geographical locations. Adolescents not only feared the social impact but also discussed the impact on self-perception, and reported that they would think of themselves as ‘weird’ or ‘weak’ for seeking help from professionals (n = 5). Family attitudes also play a role in preventing help-seeking, with adolescents reporting that their family rules prohibit conversation about mental health and that mental health concerns should be addressed exclusively within the family.

> *"Well, my mom is very much against psychologists. She thinks that the problem should be kept within the family...Yeah, you keep it under wraps, you take care of it by yourself."* (Chandra & Minkovitz, 2007)

Interestingly, these views are expressed from ethnic minority populations (De Anstiss & Ziaian, 2010) as well as studies in the USA consisting of mainly Caucasian adolescents, suggesting that these beliefs may be pervasive across cultural groups.

Fears about judgement and stigma are not limited to social groups and family; adolescents also fear being judged by mental health professionals (n = 4).

> *"There's just some stuff I would not tell doctors or nurses that I've done because they might associate to them that I seem crazy in some way ... or that I need to be put away because sometimes I have acted crazy and it's not good, but it's happened."* (Wisdom et al., 2006).

In addition to the fear of being judged, adolescents also expressed a fear that their difficulties may be 'dismissed' by mental health professionals as insignificant, or be told not to worry, that ''it'll go away'' (Fornos et al., 2005).

Strongly related to fears about stigma, adolescents also discussed concerns about confidentiality as preventing access to mental health services (n = 9); this concern was present across the studies. Confidentiality at school was emphasised in three studies (Kendal et al., 2014; Klineberg et al., 2013; Timlin-Scalera et al., 2003), due to concerns that teachers may not respect confidentiality and the impact of this on social relationships and school grades.

Adolescents also expressed concern about other negative consequences to seeking help (n = 6): that it would make things worse (Fornos et al., 2005; Fortune et al., 2008a); the possible ramifications at school (Lindsey et al., 2013; Timlin-Scalera et al., 2003), and the possible legal consequences (child protection) of disclosing difficult relationships with parents (Fornos et al., 2005; Lindsey et al., 2013). Two studies emphasised that young people were reluctant to seek help as they may hurt or offend their family (Fortune et al., 2008a; Lindsey et al., 2013), and they would not want to burden someone else with their problems (Timlin-Scalera et al., 2003).

2. Psychological treatment is not wanted/not perceived to be needed

Several studies presented data relating to adolescents' ambivalence towards psychological treatment for mental health difficulties. Young people particularly expressed a preference for self-reliance (n = 9) *"I think I'd just try to handle the situation myself"* (Del Mauro & Jackson

Williams, 2013); for informal social support (n = 3) *"I would definitely go to my friends first…even for serious things because they know me the best of anyone in my life."* (Timlin-Scalera et al., 2003); or a focus on religious coping strategies, such as prayer (n = 1),

> *"...I think that people, teenagers especially, don't get help because of what other people say about you know, how you should pray and all that 'well, you don't need no drugs because all you gotta do is pray'."* (Breland-Noble et al., 2015)

Related to this preference to manage problems alone or with informal support was an apparent lack of interest in treatment or a belief that treatment was not appropriate to their situation (n = 9). One study interpreted this as adolescents' lack of insight into mental health difficulties,

> *'...many appeared to lack insight into their own problems and need for services'* (Timlin-Scalera et al., 2003).

Other studies emphasised adolescents' perspectives that distressing experiences are 'normal' and do not necessarily require treatment (n=6),

> *"I'm a teenager, I'm supposed to have troubles…so I just dealt with it on my own"* (Wisdom et al., 2006).

Two studies also presented different perceptions about the aetiology of mental health difficulties and the impact on help-seeking. De Anstiss et al. (2010) explored the perspectives of refugees from varied cultural backgrounds, with one participant commenting:

> *"Sometimes craziness maybe come from devil cos I've known a lot of people from my cultural background (who have been victims). We have like – I don't know how to say it in English – witches, we have something like that."*

In a US-based community study, adolescents emphasised that depression can be caused by social isolation and therefore an increase in social activity may be more beneficial than treatment from mental health services,

> *"A lot of depression may stem from loneliness or being singled out, so instead of pushing them towards drugs maybe you should push them toward a YMCA or a summer camp or something ... somewhere they can have people their own age who can relate to them."* (Wisdom et al., 2006).

3. Lack of trust and confidence in mental health services and professionals

A further theme present across studies is a lack of trust and confidence in mental health services and professionals. This is slightly different to children and adolescents' belief that they do not *need* treatment, but rather addresses the belief that if treatment *was* perceived to be needed, mental health services would not be approached as they are not helpful. One study specifically relates this to previous negative experiences with services (Chandra & Minkovitz, 2007); another study emphasises adolescents' lack of hope for improvement, feeling that they are 'beyond hope' (Fortune et al., 2008a).

Two studies elicited adolescents' concerns that mental health professionals lack cultural awareness, therefore affecting the efficacy of treatment. One study was with refugees in Australia, representing a minority population (De Anstiss & Ziaian, 2010), while the other study focused on African American adolescents in the US (Lindsey et al., 2006), who expressed a perception that therapists are mainly Caucasian,

> *"And I mean it might be…a race issue because some—I think that there are some black people who close themselves off from white people. And, you know, in the mental health field, there is a majority of white people, I think."*

Some adolescents expressed concern that medication and in-patient admission may be offered, reducing the likelihood that they would seek help (Fornos et al., 2005; Wisdom et al., 2006).

> *"I didn't like the thought of a pill. I felt I shouldn't need a pill to be, to make me feel. There was a reason [I was depressed]. It's better to confront the reason than cover things I feel. It just felt artificial and I didn't like that."* (Wisdom et al., 2006)

This quote also emphasises that although as professionals we may distinguish between 'psychological' vs 'medical' treatment approaches, adolescents may not make this distinction.

Also included in this theme is the idea that some adolescents stated that treatment won't be helpful due to difficulty communicating feelings and problems. Two studies (Del Mauro & Jackson Williams, 2013; Fortune et al., 2008a) found that young people perceive difficulty with inter-personal openness and communication is a barrier to help-seeking; five studies discuss the role overwhelming emotions can have in preventing access to help.

> *"Sometime when you talk about big, big feelings you don't feel comfortable saying it."* (Del Mauro & Jackson Williams, 2013)

4. Limited understanding and awareness of mental health & services

In addition to children and adolescents' beliefs that seeking help is not needed, is not helpful and will potentially make things worse, adolescents also discussed a lack of awareness about mental health and sources of help as another important barrier to help-seeking.

Nine studies presented themes relating to a lack of awareness about mental health and related services. Three studies reported lack of awareness among adolescents about mental health difficulties, saying,

> *"I don't know" or "are you talking about special education?" or "a crazy person"* (Huggins et al., 2016).

More commonly presented was concern about the absence of information about mental health service provision and where to access help (n = 8). Studies in the UK, USA and Australia all indicated this as an important barrier, although it is interesting to note that four out of five UK-based studies presented this theme,

> *"I did not have a clue in the slightest. I didn't know there was CAMHS. For me, it's basically just knowing that they are out there, whether you need them or not, it's always good to know."* (McAndrew & Warne, 2014)

5. *Accessibility of mental health services*

A final barrier theme represented in the data was young people's perception that it is difficult to access mental health services due to practical issues. This theme was present across six included studies. These practical issues affecting accessibility include a lack of time (Becker et al., 2014); logistical difficulties getting to appointments (Becker et al., 2014; Francis et al., 2006; Pailler et al., 2009); financial concerns (Becker et al., 2014; Fornos et al., 2005; Goncalves & Moleiro, 2012), and a lack of available mental health services (Francis et al., 2006; Lindsey et al., 2013). Language issues were also cited as being a barrier to help-seeking in ethnic minority and migrant populations in Portugal (Goncalves & Moleiro, 2012).

Facilitator themes

Five over-arching facilitator themes were developed from the included studies. The most common theme present across ten studies was a belief that a trusting relationship with professionals who refer to services or provide services, such as teachers, would make it easier to access psychological treatment for mental health difficulties.

1. *Trusting relationship with referrers and providers*

Adolescents discussed the importance of being able to 'trust' professionals, and this appeared to be related to confidentiality, feeling understood, having problems normalised and an emphasis on choice and collaboration.

> *"Adults should be more aware that many children have problems and just need to know that they will be listened to...most children think that no one cares. Children should grow to understand that it is okay to tell people your problems and you are not weird or different. It makes you feel weird if you go to a school counsellor or a shrink."* (Fortune et al., 2008b)

> *"I think it's the biggest thing is…to know that it was okay, it's okay for me to tell her these things I was feeling."* (Wisdom et al., 2006)

> '*A shared theme across the stories of these conversations is the facilitator's promotion of the young person's agency, control and self-determination: the counselling is presented as a service which they may choose to access, in order to assess if it meets their needs, as they define them, and which they are free to stop at any time*' (Prior, 2012).

Adolescents appear to face a dilemma between feeling understood, which may lead them to wanting a professional of a similar culture or background to themselves, and wanting to remain anonymous. Three studies emphasised findings that adolescents would prefer a professional that they can 'trust' rather than a professional from the same social or cultural background (De Anstiss & Ziaian, 2010; Klineberg et al., 2013; Lindsey et al., 2006). These studies were all with adolescents from ethnic minority groups, from the UK, Australia and USA, suggesting that this is an important concern among these groups of participants.

> *"I can't say it [race of the provider] would make a difference at all because it's about getting help. It's about having someone that's there for you to understand what you're going through and to give you advice, to give you encouragement, to help you sort out things that you're going through. So with me, white or black doesn't really make a difference. What matters is that we're trustworthy of each other.*" (Lindsey et al., 2006)

2. *Social support and encouragement from others*

The second most prevalent facilitator theme was social support and encouragement. Adolescents in nine of the included studies discussed that active encouragement from friends, family, teachers and/or their religious community would make it easier to access psychological treatment for mental health problems.

> *''If you might be depressed you are not going to want to go but you might need someone to push you like your mom. Or someone to take you there, make you sit there, listen to the guy."* (Pailler et al., 2009)

Interestingly, adolescents' spoke of the importance of open conversations with friends and family about mental health as a facilitator to help-seeking (Chandra & Minkovitz, 2007; Timlin-

Scalera et al., 2003). This is particularly pertinent given that negative family attitudes and beliefs about help-seeking can act as a barrier. Adolescents also discussed that it may be necessary at times to pressurise or force adolescents to seek help (Fornos et al., 2005; Lindsey et al., 2013),

> *'Students reported avoiding such professional help unless they were forced to go by parents'* (Fornos et al., 2005).

3. Motivation to seek help

Children and adolescents included within the studies also discussed that feeling motivated to seek help was more likely to lead to help-seeking behaviour. Data relating to this motivation were extracted from eight studies included in the review. Three studies included a theme that adolescents were more likely to seek help if they believed they had a serious problem (Del Mauro & Jackson Williams, 2013; Timlin-Scalera et al., 2003; Wisdom et al, 2006).

> *"I probably wouldn't go to a psychologist unless it is something like really serious."* (Wisdom et al., 2006)

> *"Like if it was just a mild depression I would probably just work it over with my parents, but if it was something serious, like I was diagnosed with schizophrenia, I would go to a psychiatrist because they are trained professionally."* (Del Mauro & Jackson Williams, 2013)

One study, focusing on the role of religion in treatment trajectories in African American youth in USA reported religion to be a motivating factor in help-seeking, as religion actively discourages self-harm and suicide (Breland-Noble et al., 2015):

> *"I think that...religion might help somebody go to a counselor or therapist because what if something within their religion might be telling them that how maybe if they were thinking of hurting they self or killing their self, um, then like their religion might be telling them to do otherwise, so they need a counselor."*

Participants also expressed a view that positive attitudes and experiences of mental health treatment were also factors that make it easier or more likely for adolescents to seek help (n = 5).

> *'A few participants discussed how a friend or family member had received psychological services and were satisfied with the outcome. The teens explained how the positive experience of these individuals in their social network had shaped their personal opinions about mental health services.'* (Chandra & Minkovitz, 2007)

4. Information and awareness about mental health and related services

Seven studies discussed themes about the importance of raising awareness about mental health and mental health services. This theme is related to support and encouragement from social networks, as this is where young people are most likely to learn about mental health and related services. Young people discussed the following factors as facilitating access to support: publicising services, providing information and education, and awareness through social contacts.

> *"Well, my guidance teacher, she spoke to me and she explained everything clearly to me and she said that once I'd tried it for the first time, if I didn't want to go back, I didn't have to. It was up to me."* (Prior, 2012)

> *"There are posters all around school (for smoking), but then there's nothing for counselling or anything like that. In my school, there are more people who actually self-harm than smoke or drink. Have an assembly about self-harming."* (McAndrew & Warne, 2014)

Studies from the UK, USA and Australia all included themes relating to this concept.

5. Accessibility of services

A relatively small number of studies highlighted the role of accessibility in facilitating access to mental health services (k = 2). One UK-based study emphasised a theme related to more available services:

> *"I think there's only two counsellors in school, and there's really quite a lot of people who do it, who need counselling. We need to get more helpers; it would make the difference."* (McAndrew & Warne, 2014)

One study in the USA suggested that transportation may facilitate help-seeking (Pailler et al., 2009), although it is important to note that this study specifically asked adolescents about their attitudes towards being referred for services and what might make it easier for them to attend a mental health appointment.

1.5 Discussion

1.5.1 Interpretation of key findings

The present review synthesised findings from 23 primary studies focusing on child and adolescent perspectives about the barriers and facilitators to accessing psychological treatment for mental health difficulties. A range of perceived barriers and facilitators were identified: five barrier themes and five facilitator themes (see Table 3, above). It is clear from the current review that less studies focus on factors that *facilitate* access to mental health services in children and adolescents compared to barriers, however it is encouraging to see more emphasis placed on this area than previously (Gulliver et al., 2010). The following discussion considers the identified themes in the context of previous reviews and related studies in the literature.

The key themes clearly complement existing research in the area. ‘Concern about the negative consequences of seeking help’ and a perception that ‘treatment is not needed and/or not wanted’ were found to be the most prevalent barrier themes, consistent with previous reviews related to mental health help-seeking with adolescents and young adults (Gulliver et al., 2010; Rickwood et al., 2005; Rickwood et al., 2007) and with parents of children and adolescents (Reardon et al., 2017a).

‘Concern about the negative consequences of seeking help’ relates to concerns about confidentiality and the stigma attached to mental illness and help-seeking, as well as potentially adverse outcomes at school and on family relationships. Fears about confidentiality and stigma have previously been linked with studies conducted in rural populations (Gulliver et al., 2010), however this more recent review has shown that these concerns are present across different participant groups and geographical locations. The prevalence of this theme suggests that acknowledging the need for help is particularly difficult for young people due to the negative social implications attached to this process. This finding can be understood with reference to the ‘cycle of avoidance’ proposed by Biddle et al. (2007), which emphasises that the negative social meanings attributed to illness and being helped leads to a constant renegotiation of the threshold of when help is ‘needed’ (leading to avoidance). Other help-seeking models, such as the Health Belief Model (Rosenstock, 1966; 1974), place less focus on the role of social threat, and so the importance of this for young people may be underestimated if these are used to guide research and intervention.

The perception that professional ‘treatment is not needed or wanted’, with a preference for self-reliance or informal support, is important to consider in relation to developmental stage: most participants in studies included in this review were adolescents over the age of 12 years, and so independence and managing by themselves is likely to be particularly salient (Steinberg & Silk, 2002). It was also found that some young people normalise mental health difficulties, which according to the ‘cycle of avoidance’ (Biddle et al., 2007) may be a strategy used to avoid the negative social attributions attached to the acknowledgement of mental health difficulties. This barrier theme also provides some insight into the difficulties parents may experience when wanting to access help for their child; in a recent systematic review (Reardon et al., 2017a), parents cite their child's lack of awareness and reluctance to seek help as a common barrier to accessing mental health services for their children.

Issues concerning trust and confidence in mental health professionals and services emerged as influential to preventing and facilitating access to mental health services, also consistent with previous reviews (Gulliver et al., 2010; Rickwood et al., 2005; Rickwood et al., 2007). A 'lack of trust and confidence' was cited by young people as a barrier to access; Reardon et al. (2017a) also found that parents lack confidence in mental health services, suggesting that this is pervasive across family members and highlighting the importance of targeting this barrier at multiple levels to increase help-seeking in young people. Children and adolescents discussed assured confidentiality, an open and honest relationship, feeling understood, and collaboration as key aspects to developing a 'trusting relationship', facilitating help-seeking. This finding also makes sense in relation to the barrier 'Concern about the negative consequences of seeking help', with young people identifying a trusting relationship as a way to manage the threat attached to seeking help, and overcome concerns about healthcare providers.

In line with previous reviews, the importance of social support and encouragement from others (Gulliver et al., 2010; Rickwood et al., 2007) and feeling motivated to seek help (Gulliver et al., 2010) were also identified as important facilitator themes throughout included studies.

The facilitator theme 'Social support and encouragement from others' is consistent with research conducted by Rickwood et al. (2015), showing that family are the predominant influence in decisions about help-seeking for mental health throughout adolescence. This highlights that a supportive social network can challenge a young person's reluctance to seek help; it is therefore important to offer guidance and support to those around young people as well as to adolescents themselves.

The theme 'motivation to seek help' encapsulates young people's perspectives that they are more likely to seek help if the problem is perceived to be serious, which is interesting to consider within the context of the prominent barrier theme 'mental health treatment is not wanted/needed', and the renegotiation of the threshold at which professional treatment is required (Biddle et al., 2007). Considering the 'cycle of avoidance' (Biddle et al., 2007), which hypothesises that young people repeatedly renegotiate what a 'serious' problem is in order to avoid seeking help, the role of positive relationships and support networks may be useful to help manage the social threat of accessing support for mental health difficulties. Previous positive help-seeking experiences motivate young people to seek help, perhaps because this experience has facilitated the development of trusting relationships with mental health professionals and increased mental health literacy (Gulliver et al., 2010), both also identified as important facilitators (discussed further below).

Knowledge and awareness about mental health difficulties and how to access support was emphasised by children and young people as an important barrier and facilitator theme across a wide range of studies. In the current review, studies in the UK, USA and Australia indicated that 'limited understanding of mental health', particularly not knowing how/where to seek help acts as a barrier to help-seeking, consistent with previous reviews with young people (Gulliver et al., 2010; Rickwood et al., 2005; Rickwood et al., 2007) and parents (Reardon et al., 2017a). Corresponding directly with this theme, young people discuss the importance of raising awareness about mental health difficulties and related services to facilitate access to psychological treatment, also cited as a facilitator theme by Gulliver et al. (2010) and Reardon et al. (2017a) for young people and parents respectively.

Practical and logistical factors impacting access to mental health services were found to be less prevalent in this review than in a previous review with adolescents and young adults (Gulliver et al., 2010). In a recent review with parents, practical and logistical barriers were found to be a key overarching theme influencing access to child and adolescent mental health services (Reardon et al., 2017a). This discrepancy may be accounted for by the lack of studies using clinical populations included in the current review, and so children and adolescents may not have become aware of these barriers. It seems likely that this also reflects the developmental stage of participants in this review, who may not be concerned with the logistical factors associated with accessing treatment. Questions regarding practical and logistical barriers are often included in help-seeking surveys, and so the focus here on qualitative studies may also account for the reduced prevalence of this theme compared to other reviews.

1.5.2 Clinical implications

This review emphasises several important areas when considering how to increase access to services by young people.

The clear message from this review is that fear of negative consequences, particularly the impact of stigma, is an important barrier to accessing mental health services for children and their parents. It is particularly important that these concerns are taken seriously, and consideration is given to how confidentiality can be assured and maintained when working with young people and their families. Given the current emphasis by the Department of Education (2015) on providing mental health support through the school environment it is also important to consider alternative ways to support young people if they do not want to access mental health services at school.

In addition to increasing confidentiality, it is essential that the stigma about mental health be addressed at a cultural and societal level. The current focus in the UK, for example the ‘Heads Together’ campaign, aimed at improving public knowledge and understanding of mental health difficulties, seems particularly important to continue changing social attitudes. This review suggests that increased awareness about mental health difficulties, the development of trusting relationships with professionals, and social support and encouragement also help young people to manage the social threat attached to help-seeking.

Young people themselves emphasise that a trusting relationship with the professionals around them is likely to facilitate help-seeking for mental health difficulties. This qualitative review identifies some of the aspects young people identify as important in these relationships, including understanding, collaboration and confidentiality. It is vital to equip non-mental health professionals who work with young people with the skills and knowledge to develop validating relationships, to be able identify mental health difficulties, and awareness of available support and how to access this. This would not only provide an extra layer of support to young people but could also act to increase awareness among young people.

Finally, young people clearly perceive support and encouragement from others as a key facilitator to accessing mental health services. Families, in particular, play an important role in supporting young people with mental health difficulties, and accessing professional treatment when necessary. Parental concern can often be labelled as anxiety and parents are often left feeling dismissed by mental health services (Reardon et al., 2017a). Working with families to increase knowledge and awareness of mental health difficulties and available treatment, as well as targeting stigmatising attitudes towards parents and reducing parental ‘blame’ is therefore an important area to focus on. Families are increasingly involved in therapeutic work, as well as facilitating access to supportive services, and so it is essential that more focus is placed on understanding their experiences and supporting parents when their child has a mental health difficulty.

1.5.3 Strengths and limitations of literature review

This review focused on the perspectives of children and adolescents, synthesising research in this area and extending findings from a previous review (Gulliver et al., 2010). Previous reviews have emphasised a lack of research regarding facilitators to accessing mental health services, and this review brings together data from 23 studies to address this gap. The focus on qualitative material, without the use of more structured pre-determined data collection tools, has emphasised that young people are very focused on the threat associated with help-seeking for mental health difficulties, and appear to be less concerned with the more practical aspects of help-seeking (such as availability of services, referral processes and the logistics of getting to appointments). A further strength of this review is the focus on children and adolescents up to the age of 18 years, whereas previous reviews have included participants up to age 25 years and excluded participants under the age of 12 years; although the majority of included studies only included children in the older age range.

Thematic synthesis (Thomas & Harden, 2008) was used to analyse data from primary research studies. A strength of this approach is the use of line-by-line coding for all available data, which is thorough and facilitates the ‘translation’ of concepts across studies. At times this was difficult and required reliance on the interpretation and summaries made by the original study author; findings are therefore limited due to lack of access to the original data sources and the context of these data sources. The structure provided by this approach was useful and enabled a more transparent process.

Thomas and Harden (2008) do not advocate the use of thematic mapping as an integral part of the analytic process. On reflection, the use of thematic maps to explore the relationship between themes, as advocated by Braun and Clarke (2006) for use in thematic analysis, would have been useful for analytic purposes as well as to add clarity for the reader. A summary table (Table 3) was produced, however, to provide clarity about barrier and facilitator themes developed from the data, and to provide readers with a snapshot of the frequency with which these themes occurred across studies. This approach has been criticised by some qualitative approaches, see for example Braun and Clarke (2013), which emphasise that the frequency with which a theme is endorsed does not necessarily indicate its value in understanding the research question. Nonetheless, this approach has been used in this review in acknowledgement that this may provide an overview of findings that can be easily accessed by readers.

There are several limitations to be considered. Firstly, the search strategy for papers included in this review may not have captured all relevant articles. The search was limited to four databases and it is therefore possible that some relevant studies have been omitted. This may be particularly problematic in qualitative research (Centre for Reviews and Dissemination, 2009). Hand search strategies were utilised to increase the identification of qualitative studies, although this was limited to reference lists of articles already identified. Papers were also limited to published literature written in English; it is therefore possible that the search results are biased, although this seems unlikely within the context of the current review.

A further limitation pertains to the terminology used in the search strategy. The search terms were deliberately broad to capture articles relevant to parental as well as child and adolescent perspectives, thereby replicating the strategy used by Reardon et al. (2017a). It is possible that search terms more specific to child and adolescent perspectives may have yielded further relevant articles. The initial search also included both quantitative and qualitative papers (as advised by the Centre for Reviews and Dissemination, 2009), with papers using qualitative methodology selected for inclusion during full-text screening. This is likely to have increased the number of relevant papers sourced and, as such, increased the demand placed on the research team.

One researcher, the primary author, conducted the data extraction, quality review and coding of included papers; the results presented here may therefore be biased. Included studies varied according to their research objectives, the qualitative methodology used, the amount of data relevant to this review, and participant populations. The decision of which data to extract was not always clear; this process could be improved by increasing the number of researchers extracting data, with agreements about what constitutes ‘data’ discussed as a research team. Similarly, the quality appraisal of included papers was conducted by the primary author alone. The adapted quality appraisal tool used in this review (Kmet et al., 2004) provides limited information about judging different aspects of quality, and this was experienced to be a largely subjective process. To reduce bias, it would be beneficial for more than one researcher to conduct the quality appraisal, with decisions about quality ratings agreed as a research team. Finally, one researcher also coded the extracted data into line-by-line codes. These initial codes and developed themes were reviewed and discussed by the research team in an attempt to reduce researcher bias. Qualitative research is a subjective process, and so an audit trail has been provided as far as possible to increase the transparency of the findings.

1.5.4 Recommendations for future research

This review included participants from largely non-clinical populations, considering general mental health difficulties. It is likely that a different emphasis on key barriers and facilitators may emerge if clinical populations were the focus of the review, or for different types of mental health difficulties; it may be useful to develop research which looks at barriers and facilitators to accessing services for specific diagnostic presentations.

Research exploring facilitators needs further consideration, there continues to be less research about facilitating factors, with most research focusing on barriers to access. It is particularly important to continue asking young people directly what factors would make it easier to access services, rather than inferring this from identified barriers.

1.5.5 Conclusions

The findings suggest a number of ways forward, particularly the need to raise public awareness and understanding of mental health difficulties and how to access available services. The need for mental health services to work more flexibly with other service providers for young people is also indicated, to support them to build trusting relationships and provide preventative input, as well as facilitating access to more specialised services when appropriate. Further research would also be useful to explore how the systems around children and young people provide support, particularly families. There is currently little known about familial experiences of supporting a child with a mental health difficulty. This would be a useful area to explore in more detail given the crucial role families have in encouraging their child to access help; it would also provide increased understanding amongst professionals working with young people and their families.

Chapter 2: Empirical Paper

Experiences of parenting a child with an anxiety disorder: a secondary analysis of qualitative data.

2.1 Introduction

2.1.1 Mental health difficulties in childhood and adolescence

A significant number of children and adolescents experience mental health difficulties, with estimates that at least one in ten young people in the UK will develop a diagnosable mental health disorder (Green et al., 2005). The most common mental health difficulties experienced by young people are conduct disorders, hyperkinetic disorders, depression and anxiety disorders (Green at al., 2005). Anxiety disorders affect approximately one child in every classroom in the UK (Green et al., 2005), with a worldwide-pooled prevalence rate in childhood and adolescence of approximately 6.5% (Polanczyk, Salum, Sugaya, Caye & Rohde, 2015). The average age of onset is age 11 years (Kessler, Chiu, Demler & Walters, 2005b).

2.1.2 Anxiety disorders in childhood

An ‘anxiety disorder’ is a broad description for a range of psychiatric diagnoses, with Separation Anxiety Disorder, Specific Phobia and Social Anxiety Disorder the most common experienced by children (Hill, Waite & Creswell, 2016). Anxiety disorders are characterised by excessive fear, worry or anxiety that causes significant distress or impact on everyday life (Creswell, Cooper & Murray, 2015). Young people often present with more than one type of anxiety disorder and will frequently experience co-morbid depression and behavioural disorders (Lewinsohn, Zinbarg, Seeley, Lewinsohn & Sack., 1997).

Anxiety disorders in childhood and adolescence are unlikely to remit without treatment (Bittner et al., 2007) and are associated with adverse ‘life course outcomes’ (Woodward & Fergusson, 2001), such as poorer academic attainment (Duchesne, Vitaro, Larose & Tremblay, 2008) and lower earnings in adulthood (Knapp, King, Healey & Thomas, 2011). There are significant links between childhood, adolescent and adult anxiety (Pine, Cohen, Gurley, Brook & Ma, 1998) and young people with anxiety disorders also have an increased risk of developing depression and other mental health disorders in adulthood (Bittner et al., 2007; Costello, Mustillo, Erkanli, Keeler & Angold, 2003). Intervention to prevent anxiety disorders, or to treat these difficulties at an early stage, is therefore important.

2.1.3 Treatment for anxiety disorders

Effective interventions are available for children and adolescents presenting with an anxiety disorder (Creswell, Waite & Cooper, 2014; James, James, Cowdrey, Soler & Choke, 2015) but, as with other mental health difficulties, treatment is often not accessed. Only one third of children who need treatment reach the appropriate services (Merikangas, et al. 2010; Chavira, et al., 2004). Difficulties accessing services has been exacerbated by the current economic climate in the UK, which has led to a loss of funding for prevention and early intervention services; referrals are increasingly only accepted by mental health services when families are at crisis point (BPS, 2015). More parents are therefore managing their child's mental health difficulties at home with little support from external services.

2.1.4 Role of parents

Parents play an important role when a child experiences difficulty with their mental health. They are likely to be the first to notice signs and provide on-going support to manage symptoms (Sonuga-Barke & Balding, 1993). Due to their developmental stage, children are usually dependant on their parents to access help and support; with younger children needing more support from their parents to seek help (Farmer, Burns, Angold & Cotello, 1997). Parents most often take responsibility for managing treatment attendance and adherence (Nock & Ferriter, 2005), and are increasingly involved in treatment delivery for anxiety disorders (see for example, Thirlwall et al., 2013).

For those children and adolescents who *do* access and receive an evidence-based intervention for their anxiety disorder, full recovery is not always achieved. A recent review concluded that approximately 60% of children recover following treatment (Warwick et al., 2017); thus, even after accessing services a significant number of children continue to live with debilitating levels of anxiety.

Despite the prevalence of childhood anxiety disorders and the increased number of families managing their child's difficulties without support from appropriate services, currently little is known about parents' experiences of managing their child's anxiety, or the impact of this on parents and other family members.

2.1.5 Parenting and anxiety disorders

Research conducted specifically with parents of young people diagnosed with an anxiety disorder has mainly focused on the influence of family factors in the development and management of anxiety disorders (Rapee, 2012). This focus on the family environment is underpinned by learning theory, which suggests that anxiety is learnt through the modelling of anxious behaviour, the transfer of information about the threatening nature of the environment, and reinforcement of anxious or avoidant behaviour (Bandura, 1986; Rachman, 1977; Rapee, 2002). Research focused on parenting behaviours, often using observational methodological designs, indicates that parental control and overprotection play a significant role in the development of child anxiety (Rapee, 2012). It has also been found that parenting style is adapted when a child has an anxiety disorder, emphasising the interactive relationship between parent and child behaviour (Creswell et al., 2015).

This research highlights the key role parents play in the development, maintenance and management of childhood anxiety disorders, including facilitating treatment access and engagement. However, this research tells us little about parents' experiences of recognising and managing their child's anxiety from their own perspective, or the perceived impact on parents and other family members.

2.1.6 Parenting experiences

Research exploring parenting experiences and mental health difficulties in children and adolescents has focused on parental burden, stress and strain (Simpson, Suarez & Connolly, 2012; Angold et al. 1998), parental satisfaction with child and adolescent mental health services (e.g. Bone, O'reilly, Karim & Vostanis, 2014), and parental help-seeking beliefs and behaviours (Reardon et al., 2017a; Boulter & Rickwood, 2013). In a recent systematic review of parents' perceptions of seeking help for their child's mental health difficulties (Reardon et al., 2017a) is was found that parents report difficulty recognising symptoms, and that experiences of blame and stigma prevent access to services. While this research provides some insight into parental experiences, these studies often utilise self-report measures and therefore provide little context and meaning behind parents' responses.

To address this gap there is a growing body of qualitative research focusing on experiences of supporting, parenting and seeking help for a child or adolescent with a mental health difficulty from parents' perspectives. To date, this research has focused on parents of young people with a range of mental health difficulties, including depression (Stapley, Midgley & Target, 2015), self-harm (McDonald, O'Brien & Jackson, 2007), attention-deficit hyperactivity disorder (ADHD;

Firmin & Phillips, 2009), obsessive-compulsive disorder (OCD; Futh, Simonds & Micali, 2012), bi-polar disorder (Maskill, Crowe, Luty & Joyce, 2010), psychosis (McCann, Lubman & Clark, 2011), schizophrenia (Knock, Kline, Schiffman, Maynard & Reeves, 2011), eating disorders (Cottee-Lane, Pistrang & Bryant-Waugh, 2004) and substance abuse (Choate, 2011).

This research indicates some of the difficulties experienced when parenting a child with mental health difficulties. Stapley et al. (2015) discuss parents' lack of awareness that their child (ages 11-17 years) had a depressive disorder, initially confusing symptoms with 'normal' adolescent behaviours. Parents similarly discussed a 'slow recognition' that their child had an eating disorder and guilt about not accessing treatment sooner (Cottee-Lane et al., 2004). McDonald et al. (2007) and Futh et al. (2012) discuss themes related to parents' sense of uncertainty about how to understand and manage their child's symptoms, with some parents 'normalising' mental health symptoms. Parents manage this uncertainty by actively trying to understand their child's presentation (Cottee-Lane et al., 2004; Futh et al., 2012; McDonald et al., 2007).

The emotional impact on parents is also emphasised in these qualitative studies, which highlight the sacrifices parents have made and the burden and demand placed on them (Knock et al., 201; Maskill et al., 2010; McCann et al. 2011). Parents describe the emotional 'turmoil' of parenting a child with a mental health difficulty, including feelings of anger, distress, guilt and shame (Cottee-Lane et al., 2004; Futh et al., 2012; McDonald et al., 2007). The impact of stigma and self-stigma in parents of children with mental health difficulties has also been increasingly emphasised (Eaton, Ohan, Stritzke & Corrigan, 2016; Eaton, Ohan, Stritzke, Courtauld & Corrigan, 2017; McCann et al., 2011; Moses, 2010).

This increased awareness about the experiences of parenting young people with mental health difficulties is useful and informative, providing insight about how to improve psychologically-informed support for these parents, potentially leading to better outcomes for young people. Awareness of parents' experiences can also inform interventions aimed at improving access to and engagement with professional treatment. There is, however, no published research to date that explores the experiences of parents' who have a child with an anxiety disorder, which is surprising given the prevalence of anxiety disorders in childhood. The current study aims to address this gap.

2.1.7 Rationale for current study

It is important to understand the experiences of parents who have a child with an anxiety disorder. It is most often a child's parents who are the first to recognise and manage difficulties at home, facilitate access to treatment, and support their child through therapy. Given that a significant number of children do not access services or continue to live with an anxiety disorder even after receiving appropriate treatment, parents play an important role in providing on-going support to children living with an anxiety disorder.

Understanding parents' experiences of recognising and managing their child's anxiety can therefore help to identify ways to provide psychologically-informed support to parents, leading to better outcomes for young people. Many parents do not seek help for their child's anxiety disorder, often due to difficulty recognising difficulties or the need for intervention. Awareness of parents' experiences can therefore inform interventions aimed at improving access to and engagement with professional treatment, and to encourage parental participation, for example by raising awareness of 'typical parenting experiences'. Even if mental health problems are identified, fear of blame and stigma can prevent children and families seeking help (BPS, 2015). Raising awareness about the experiences of parenting a child with an anxiety disorder, particularly among services working with children, may increase understanding among professionals and reduce the sense of blame and stigma reported by parents (Francis, 2012; Reardon et al., 2017a).

2.1.8 Aim

The aim of this qualitative study was therefore to explore the experiences of parenting a child (aged 7 to 11 years) with diagnostic levels of anxiety in England. Given the paucity of research in this area a qualitative approach was used to provide a rich and detailed understanding of parents' narratives.

It was decided to focus on children aged 7 to 11 years as research indicates that 50% of individuals with a lifetime prevalence of anxiety disorder will have experienced onset by age 11 years (Kessler et al., 2005a). Understanding parents' experiences of recognising and managing difficulties within a younger age group was therefore deemed important to inform early intervention efforts. Research has also shown qualitative differences between child and adolescent anxiety (Waite & Creswell, 2014), with parents playing a key role in the management of childhood anxiety.

This research focused on parents' experiences of recognising, understanding and managing their child's anxiety. This study specifically does not focus on parents' experiences of accessing *professional treatment* for their child’s anxiety, as this has been reported elsewhere (Reardon, Harvey, Young, O’Brien & Creswell, 2017b). It should also be noted that although the term ‘parent’ is used, the majority of the sample are mothers.

2.2 Method

2.2.1 Design

This research uses a qualitative design to explore parents' views and experiences of having a child with an anxiety disorder. This study is a secondary analysis of an existing dataset collected for the 'Improving Access to Child Anxiety Treatment' project (Reardon et al., 2017b).

Secondary analysis refers to the use of pre-existing qualitative data to find answers to research questions that differ to the questions asked in the original research (Hinds, Vogel & Clarke-Steffen, 1997). Heaton (2004; 2008) describes the purpose of secondary analysis as investigating new or additional research questions and emphasises the potential of data re-use to maximise participation.

This secondary analysis has a separate focus from that conducted in the original study, which explored parents' experiences of seeking and accessing professional help for anxiety disorders in children. The original research team reported that parents spoke repeatedly about the impact of having a child with an anxiety disorder, on themselves as parents and on their family, during the qualitative interviews, but these experiences could not be explored within the initial study. It was therefore agreed that a secondary qualitative analysis would be appropriate to focus specifically on these experiences.

2.2.2 Description of the primary data source

Transcribed interview material from the 'Improving Access to Child Anxiety' study was used in the current research. In the primary study semi-structured interviews were conducted with 18 parents of children (ages 7-11 years) meeting criteria for diagnosis of an anxiety disorder; 16 interviews were conducted in total (two parents were present in two of the interviews). All 16 anonymised interview transcripts from the primary study were used as data for the secondary analysis.

2.2.3 Recruitment to the primary study

Criteria for inclusion in the primary study were: a family where a child (aged 7-11 years at the time of recruitment) meets diagnostic criteria for an anxiety disorder. Exclusion criteria: unable to speak English; anxiety disorder is not the primary diagnosis. Schools and families were offered a small financial incentive to participate, and parents were aware that following diagnostic assessment a report would be provided which could facilitate referral to mental health services (if appropriate). Families were also provided with a list of resources related to childhood anxiety disorder.

The ‘Improving Access to Child Anxiety Treatment’ study (Reardon et al., 2017b) aimed specifically to recruit a heterogeneous sample of children and their parents from the community, rather than from a clinical population. In order to achieve this recruitment took place in three stages, outlined below.

Stage 1 – Identifying schools to participate in the study

During the first stage of recruitment 102 primary and junior schools in England were contacted during March-October 2015 and invited to participate in the study. Schools with a diverse demographic population across different geographic regions of England were contacted. Ten schools were recruited to the project, located in Buckinghamshire, East Sussex, Hampshire, Middlesex, Northumberland, Surrey and Worcestershire. Nine of the participating schools were state-funded and one was an independent school. In the state-funded schools’ children receiving free school meals varied from 2.1-57.5% of children.

Stage 2 – Anxiety screening within schools

Information about the study, parent consent forms and questionnaires for parents were distributed by the original research team to all parents and/or carers of children in Years 3-6 (ages 7-11 years) in all 10 schools recruited into the study. The information was available to schools and parents in an electronic and/or paper format and the questionnaires took approximately 10 minutes to complete.

The research team then visited the participating school, and children whose parents had provided consent were asked to complete anxiety screening questionnaires within school. This stage of data collection took place in groups and lasted approximately 20 minutes. Teachers also completed anxiety screening questionnaires for each of the participating children, either online or on paper; this took approximately 5 minutes per child. Demographic information relating to each participating child, using school records, was also collected by researchers during the school visit.

Parents of children identified as having elevated levels of anxiety (based on child, parent or teacher report), using the Spence Child’s Anxiety Scale (SCAS; Spence, 1998) were invited to participate in Stage 3.

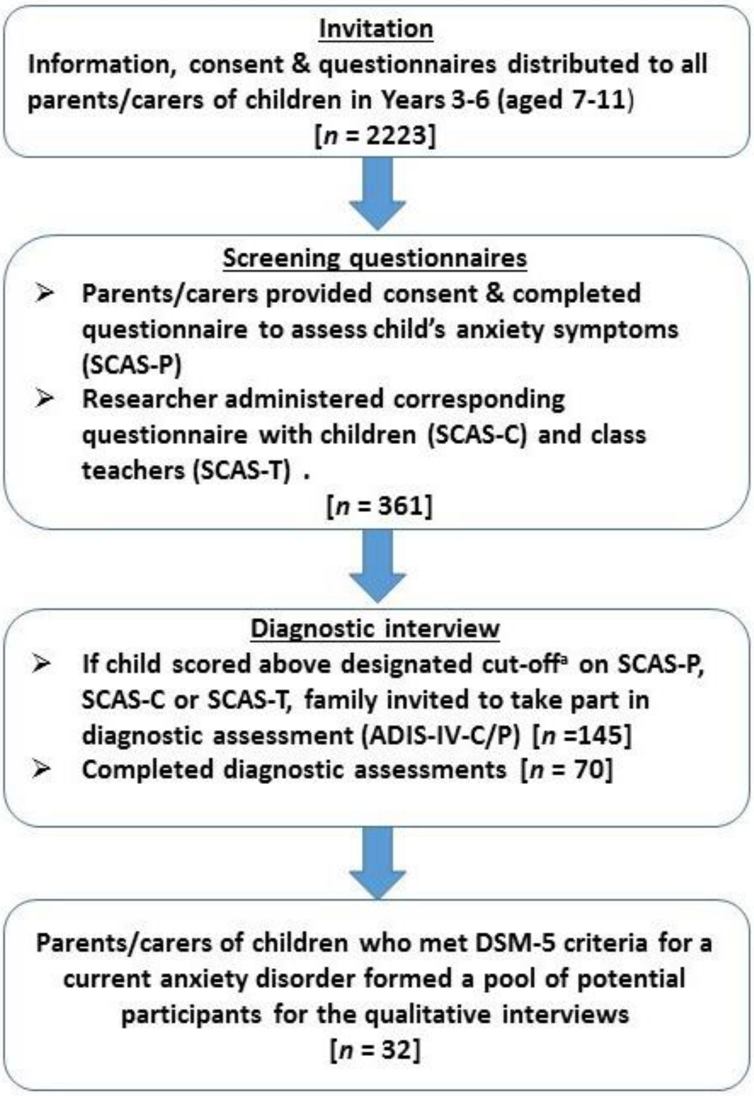
Stage 3 – Diagnostic interviews

Parents agreeing to participate in this stage of the research were invited to take part in a more detailed assessment of their child's anxiety, using the Anxiety Disorder Interview Schedule (ADISC/P; Silverman and Albano 1996). This assessment was used to identify children who meet DSM-5 (American Psychiatric Association, 2013) criteria for a current anxiety disorder. Assessments were conducted by two researchers in a location convenient for the family; parents and their child were interviewed separately for approximately one hour each.

Parents of children meeting DSM-5 (American Psychiatric Association, 2013) criteria for a current anxiety disorder were then invited to participate in a follow-up interview about their help-seeking experiences. Thirty-two families were identified as meeting the inclusion criteria for the interview study.

Further details about measures used within the primary study can be found in Appendix B6.

Figure 2. *Screening process within recruited schools to identify potential participants.*



Invitation
Information, consent & questionnaires distributed to all parents/carers of children in Years 3-6 (aged 7-11)
[*n* = 2223]

Screening questionnaires

- Parents/carers provided consent & completed questionnaire to assess child's anxiety symptoms (SCAS-P)
- Researcher administered corresponding questionnaire with children (SCAS-C) and class teachers (SCAS-T) .

[*n* = 361]

Diagnostic interview

- If child scored above designated cut-off[a] on SCAS-P, SCAS-C or SCAS-T, family invited to take part in diagnostic assessment (ADIS-IV-C/P) [*n* =145]
- Completed diagnostic assessments [*n* = 70]

Parents/carers of children who met DSM-5 criteria for a current anxiety disorder formed a pool of potential participants for the qualitative interviews
[*n* = 32]

Note: SCAS-P = Spence Children's Anxiety Scale-Parent Version; SCAS-C = Spence Children's Anxiety Scale-Child Version; SCAS-T = Spence Children's Anxiety Scale-Teacher Version.

[a] Published cut-scores on the SCAS-C indicating 'elevated' anxiety symptoms (for girls and boys aged 8-11 years) were used (available on www.scaswebsite.com). Published cut-scores are not available for the SCAS-P or SCAS-T, therefore the following were used as cut-scores: SCAS-P mean total score+ 1 standard deviation in a normal sample as published on www.scaswebsite.com; SCAS-T mean total score+ 1 standard deviation in the current study.

2.2.4 Primary data collection: qualitative interviews

Parents of children meeting criteria were invited to take part in a follow-up, qualitative interview to collect rich and in-depth information exploring their views and experiences of recognising and seeking help for their child's anxiety difficulties. Five key topics were explored: i) knowledge and beliefs about anxiety in children; ii) recognition of their child's anxiety difficulties;

iii) knowledge and beliefs surrounding help seeking; iv) beliefs and experiences of services; and v) suggestions for improvements to the help seeking process. The topic guide was developed by the original research team in line with findings from existing literature. See Appendix B1 for interview topic guide.

The semi-structured format of the interview questions allowed the interviewer to explore participants' views and meanings in more depth when appropriate to the research aims. Interviews were conducted by the original research author, a doctoral psychology student with clinical and interviewing experience. Interviews were audio-recorded and lasted from 33 to 79 minutes. Interviews took place at a location convenient for the parent(s); four interviews were conducted face-to-face and 12 were conducted by telephone. Interviews were transcribed verbatim. To protect the confidentiality of participants, all identifiable details were removed from the interview transcript and participants were allocated a participant number. Pseudonyms were used in place of children's names when using quotations from the interview material.

2.2.5 Primary data analysis

In the primary study the transcribed interview material was analysed using thematic analysis and focused on themes related to parents' experiences of seeking and accessing professional help for their child's anxiety disorder. Only interview material relating to this research question was included in the primary analysis.

2.2.6 Participants

In total, 32 families were eligible for inclusion in the interview study and agreed to be available for participation. Purposive sampling was used to select 20 families from this sampling pool. The following characteristics were considered during the sampling process to increase the heterogeneity of the sample: i) child age and gender; ii) type and severity of child anxiety disorders, iii) prior help seeking for the child's anxiety difficulties, iv) socio-economic status and v) geographic location.

Interviews were conducted with 18 parents, at which point the original research team noted that data saturation had been reached; analyses was no longer generating any substantially new concepts or ideas (Braun & Clarke, 2006). Most interviews were conducted with mothers only (14 interviews) and two interviews were conducted with both the child's mother and father. The participants' ages ranged from 25 to 54 years, with a median age of 43.5 years. Ethnicity was not recorded for parents, but the ethnicity of all children included in the study was recorded as ‘White’ (13 were classified as ‘white British’; three children were classified as ‘white, any other background’). Nine families were categorised as having a higher/professional socio-economic status and three families that participated received free school meals for their child/children.

Eleven participating families had a daughter identified as meeting diagnostic criteria for an anxiety disorder in this study; five families had a son. Children’s ages ranged from 7 to 11 years, with a median age of 8.9 years. Children had between one and three anxiety disorder diagnoses, including separation anxiety disorder (*n* = 3), social anxiety disorder (*n* = 5), generalised anxiety disorder (*n* = 10) and specific phobias (*n* = 7). Clinical severity ratings (CSRs) for the primary disorders ranged from 4-6. Four children had a non-anxiety comorbid disorder (depression, *n* = 1; attention deficit hyperactivity disorder, *n* = 2; oppositional defiant disorder, *n* = 1). Just over half of families included in the study had sought help or advice from a professional (*n* = 9), while 7 families reported that they had not sought help or advice from a professional. Six children had received a referral to Child and Adolescent Mental Health Services (CAMHS) either for anxiety or other difficulties. Table 5 provides a summary of participant characteristics (taken from Reardon et al., 2017b).

A summary of participant characteristics can be found in Appendix B7 (taken from Reardon et al., 2017b).

2.2.7 Secondary analysis of qualitative data: methodological considerations

Heaton (2008) emphasises the lack of clear and consistently accepted guidelines for the methodology of secondary qualitative analysis, and researchers have expressed concern about the reuse of qualitative data. In particular, there is concern about whether data collected for one purpose can be meaningfully re-used for a different purpose. Some qualitative researchers argue that meaning is situation and context-specific and data therefore cannot be used by a different researcher to explore a different research question (see for example, Morrow, Boddy & Lamb, 2014). The data used in the current project was shared informally. Audio recordings of the primary research interviews were not available, which limited awareness of participants’ meanings. The primary research team provided support with the secondary analysis, providing increased awareness about the context of the data. Whilst the primary author (GEB) conducted all stages of the secondary analysis, the primary researchers advised and supported the development of initial codes and themes.

A further issue relates to the ‘problem of data fit’ (Heaton, 2008): consideration of whether the primary data can meet the aims of the secondary study. Long-Sutehall et al. (2010) advise careful consideration of the assessment of fit between the primary dataset and the secondary research questions and recommend that the research questions for the secondary analysis be close to those of the primary research. It is also recommended that data collection and analytic techniques in the primary dataset are similar to those used in the secondary analysis. As the current study is a supplementary analysis, providing a more in-depth analysis of an issue that emerged (and was not addressed) in the primary study, this secondary analysis was considered appropriate. Indeed, in the current analysis it was found that a large volume of data was available in the primary data source to address the secondary research aims.

Questions have also been raised about how best to verify findings in secondary analysis, and whether verification is appropriate in qualitative research. Smith (1996) outlines several methods of verification in qualitative methodology, including internal coherence and the presentation of evidence. One method of verification is to conduct ‘member checks’, where researchers return to the original study population to present findings and explore whether these are meaningful and represent their narratives. This is more difficult in secondary analysis and was not possible within the current study. Particular attention was therefore paid to providing an ‘audit trail’ (Pidgeon & Henwood, 1996) to provide transparency about the credibility of the analysis.

2.2.8 Ethical considerations

Ethical approval was obtained from the University of Reading Research Ethics Committee and the University of Southampton Ethics and Research Governance Committee (see Appendix B2; ERGO study ID number 26383). This covered the use of data for purposes relevant to the present study.

Concerns about the ethics of data reuse have been raised (see for example, Morrow, Boddy & Lamb, 2014). It has been emphasised that informed consent cannot be presumed in secondary analysis. Heaton (2008) recommends that professional judgement be used to consider whether data re-use breaches the contract between participants and the primary research team. It is particularly important to consider the fit between the original and secondary research questions, and whether the new questions shift the focus of the original research intention.

In the current study, the secondary research aims were generated during the analysis for the primary study and are closely related to the intention of the primary research; therefore judgement was made that consent gained in the primary research was sufficient to carry out this secondary analysis.

During the primary study informed consent was obtained from all participating parents at each stage of the study (see Appendix B3 for consent forms), and informed assent obtained from all children included in the screening stage of the study. Participants were provided with an information sheet explaining the rationale for the research, the purpose of the study and emphasising the voluntary nature of participation. Children were provided with a simplified version of this information. It was also made clear to parents that anonymised quotes from their interviews may be used in the write up of the project. Children and parents in agreement signed a consent form. Data was stored on a secure network at the University of Reading. University of Reading and University of Southampton guidelines on data protection and confidentiality were followed.

2.2.9 Analytic approach and epistemological orientation

In the secondary analysis interview material was explored using thematic analysis (Braun & Clarke, 2006), and focused on parental experiences of having an anxious child. Thematic analysis was used to ‘identify, analyse and report’ themes across this qualitative dataset (Braun & Clarke, 2006), looking for similarities and patterns, but also differences and nuances in participant’s narratives. Thematic analysis was chosen as a method because of its systematic approach; clear guidelines about how to develop this type of analysis have been produced (Howitt, 2010). Thematic analysis facilitates the organisation and ‘thick’ description of a data set (Geertz, 1973), but also moves beyond this to *interpret* the patterns identified in the data (Boyatzis, 1998).

Willig (2013) emphasises that thematic analysis is not tied to a particular epistemological framework, and therefore provides more flexibility than other qualitative research methods. Nonetheless, it is important to be clear about the theoretical assumptions that have guided the research (Clarke, Braun & Hayfield, 2015).

An inductive, qualitative approach to Thematic Analysis was used, in line with a critical-realist standpoint (Braun & Clarke, 2013). Situated in post-modern thinking, this approach moves away from ‘representationalism’, the assumption that research can directly describe reality (Gergen, 1994). This perspective emphasises that meaning is context-dependent rather than ‘truth’, and as such research from a critical-realist perspective is interested in participants’ meanings and interpretations about aspects of their social world. Furthermore, the researcher and research process cannot be ‘objective’ and are shaped by the researchers own taken-for-granted assumptions. Reflexivity on behalf of the researcher is therefore required, as researchers’ own interests and view of the world shape the research process (King, 1996).

2.2.10 Reflexivity

This research study is a secondary analysis of qualitative data, and as such the primary research team designed the research project, and data collection had taken place prior to my involvement in the study. My own interests and experiences have shaped the research question I chose to focus on in this analysis, as well as my interpretations of the data and the themes developed. Acknowledgement of aspects of myself that may have been particularly influential is therefore required. As a final year trainee clinical psychologist, my own understanding of the aetiology and treatment for anxiety disorders is likely to have influenced my interpretation of the data and therefore the themes developed in the analysis. Identifying with a systemic therapeutic orientation, I was particularly interested in the social discourses shaping participants responses, especially related to the internalisation of difficulties, power attributed to medical professionals and the role of motherhood. In addition, my own position as a mother with children in the British school system is also likely to have influenced my interpretation of the data. To maintain awareness of my own role in the research process (Braun & Clarke, 2006), a reflective log was used (Reinharz, 1997), as well as discussion in research supervision about my assumptions and interpretations (see Appendix B4 for an extract from my reflexive log for this study). This facilitated the process of looking for alternative interpretations of the data, but also increased my awareness of how my own expectations and biases impacted my interpretations.

2.2.11 Analytic method

Interview transcripts were uploaded into NVivo Version 11 (Bazeley & Jackson, 2013), a qualitative software programme, used to organise data and support analysis. The use of NVivo can also increase the flexibility and accuracy of coding (Burnard, Gill, Stewart, Treasure & Chadwick, 2008). A thematic analysis of the interviews was then conducted, focusing on data related to the following research question: what are the experiences of parents of children meeting diagnostic criteria for anxiety disorder? The analysis was inductive, meaning that codes and themes were developed from the data rather than generated from pre-existing theory and applied to the data.

This study followed the six-phase approach to thematic analysis outlined by Braun and Clarke (2006); each stage is discussed below. An iterative process of coding was used, as each new transcript was coded, codes across previous transcripts were constantly reviewed and refined. Attention was given to manifest and latent meaning within the data.

(1) *Data familiarisation*: Each interview transcript was read and reread, and notes were made about possible themes. Discussion took place with the original research team to consider the developing themes, and to ensure this analysis was distinct from the primary qualitative analysis of this

dataset. From this discussion, it was agreed that coding should focus directly on aspects of the dataset relating to experiences of parenting a child with an anxiety disorder, but not code data relating to parents' experiences of seeking or accessing *professional support* for anxiety (as this had been the focus of a previous qualitative analysis, Reardon et al., 2017b).

(2) *Initial coding*, using NVivo10 to facilitate this process. Each transcript was systematically coded by highlighting potentially relevant sections of text and allocating a short label to describe the content of the text in relation to the research question. Some segments of text were allocated more than one code when different meanings were interpreted from the same section of data. An iterative process, with constant comparison between the data and researchers' interpretations, was used to keep emerging themes close to the original data set (Pidgeon & Henwood, 1996). At the end of this stage all transcripts had been coded and a long list of initial codes had been recorded. All data given the same code across transcripts and within each transcript were grouped together in NVivo. During initial coding discussion took place with the primary research team to ensure understanding about the context of the data, and to decipher codes belonging to the primary research question. Any codes relating to 'professional treatment' were removed from this analysis.

(3) In the next phase *potential themes* were developed. Initial codes (and associated data extracts) were clustered together in NVivo according to their meaning, and a process of interpreting the data for meaningful themes took place. Potentially meaningful themes and sub-themes were developed using thematic 'mapping' to facilitate this process and in discussion with the research team.

(4) During the *refining themes* stage, data extracts relating to each initial code, and grouped into sub-themes and over-arching themes, were read to check the relevance of each extract to each theme, and to ensure enough data was available to support each theme. A 'thematic map' of potential themes and codes was developed to ensure distinctions between themes, but also the relationships between themes and codes (see Figure 3 for final thematic map). The developing themes were then discussed and reviewed with the research team, and suggestions made for the elaboration, amendment and labelling of themes.

(5) *Defining and naming themes*: Each main theme and subtheme was given a name and definition representing the content of that theme.

(6) *Reporting the findings*: Braun & Clarke (2014) emphasise that writing up thematic analysis is integral to the analytic process, and as such these six stages are not discrete but inter-related. Data extracts were used in the write-up to increase validity and to relate themes back to the research question (Yardley, 2015).

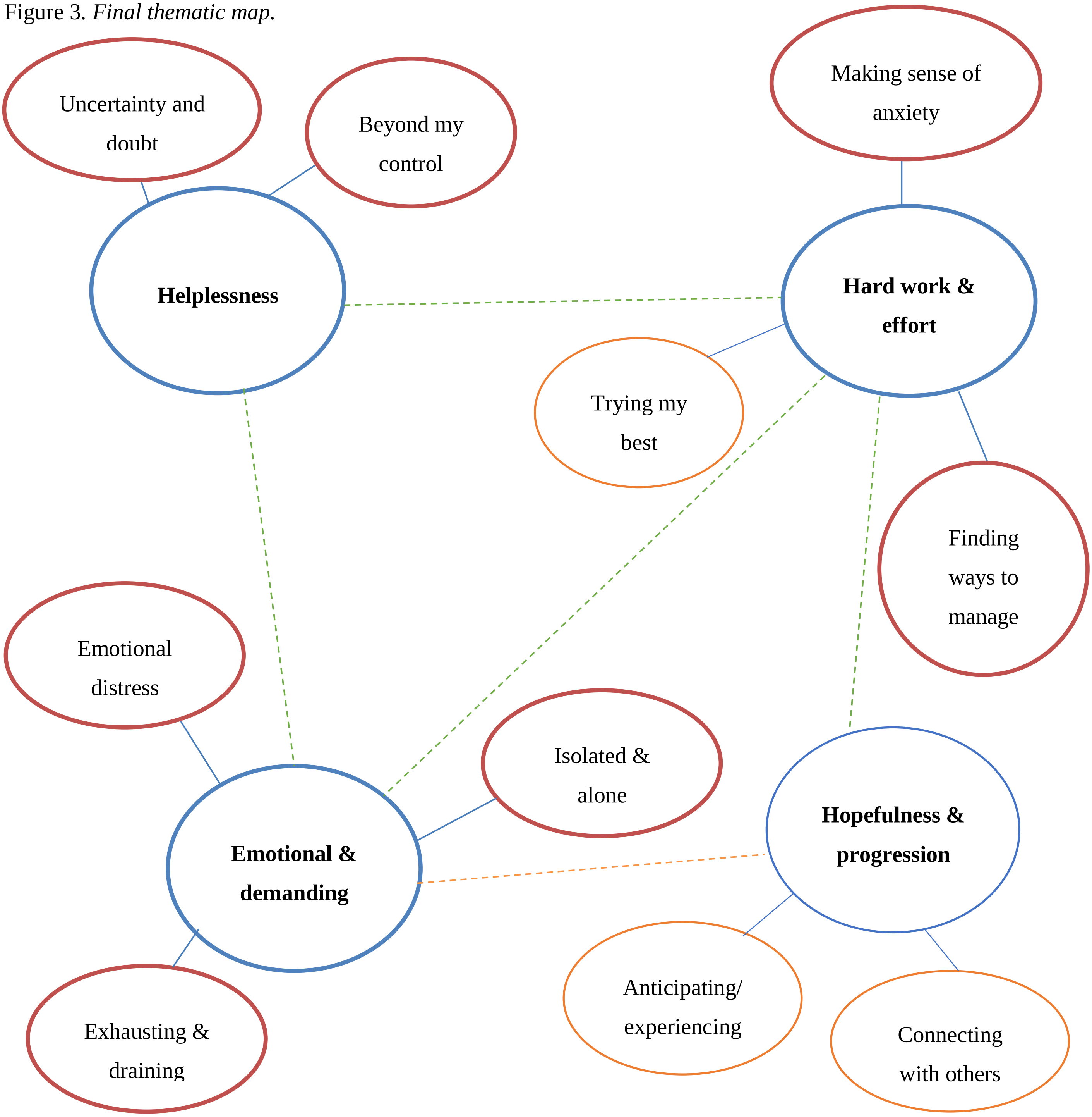
Braun & Clarke (2013) emphasise that the use of frequency counts in qualitative analysis is controversial, reflecting a realist assumption that indicating precise numbers of participants provides more meaningful or accurate information. A qualitative perspective emphasises that the number of people endorsing a particular perspective does not necessarily determine its' value in understanding the research question (Braun & Clarke, 2006). Furthermore, due to the open and interactive nature of data collection in qualitative analysis it makes little sense to compare the proportions of participants endorsing a particular perspective, because not all participants will have been asked the same questions or discussed the same issues and so we cannot assume that those *not* discussing a particular issue did not also think this or experience this; thus, we have no way of interpreting what is not discussed in qualitative data (Huxley, Clarke & Halliwell, 2011). Frequency counts were therefore not used in this analysis.

2.3 Results

The findings will be discussed in relation to the four over-arching themes and 10 related themes developed through the thematic analysis. Figure 3 provides a 'thematic map' and indicates the relationships between over-arching themes (using a broken line). A more detailed table of over-arching themes, with related themes and sub-themes developed in the analysis can be seen in Appendix B5.

Four over-arching themes were developed from the data. Parents' expressed a sense of helplessness relating to understanding their child's behaviour and how to manage their child's difficulties; parents also talked of the emotional demands associated with their experiences, closely related to their sense of helplessness. Alongside the emotional impact of living with an anxious child and feeling powerless to help, parents also described working hard to learn more about anxiety and to find ways to support their child. The theme 'hopefulness and progression' relates to this persistence and hard work, particularly connecting with others for support and to learn more about managing anxiety. Parents also discussed noticing improvements in their child's presentation and an optimism that the anxiety would improve. To some extent these themes reflect a sense of conflict within parents' stories, balancing the demands placed on them with the hope that their child will overcome their difficulties.

Figure 3. *Final thematic map.*



Each theme is discussed in more detail below and is illustrated with examples from the interview material (in italics). Each quotation is identified by the participant number and whether this comment was made by a mother (M) or father (F).

2.3.1 Helplessness

One of the main themes developed in the analysis relates to the sense of helplessness expressed by parents, perceiving their child's anxiety to be beyond their control and feeling uncertain about whether their child has a problem or how best to provide support.

Beyond my control

Participants discussed that their child's anxiety and the factors that trigger, exacerbate or improve their child's anxiety feel outside of their control. This lack of perceived influence over anxiety partly relates to the nature of anxiety itself: parents describe anxiety as being quick to escalate and difficult to manage, and frustration that the anxiety does not seem to dissipate by itself:

> *"…you think maybe they are normal because all children are afraid of the dark and it will just pass when he gets older or maybe when we talk to him and explain it will sort of go away but it didn't, and it was getting worse…" (P7, M)*

Participants also referred to the impact of school issues, peer relationships and 'real life' on their child's anxiety, with parents feeling unable to change or influence these factors, and unable to support their child when they are in the school environment:

> *"At home she's constantly worrying about something or something has happened in school and it's spilled out to home and she then continues to worry about it at home even though I can't necessarily do anything." (P6, M)*

An interesting sub-theme is a view that children 'know too much' these days, and how 'times have changed' from when parents were children, and therefore parents discuss not knowing how to manage these 'modern-day' problems. Some parents felt concerned that awareness about mental health, world news, terrorism, and human rights is likely to have added to their child's anxiety, with the internet and social media exacerbating the problem:

> *"I think she's just becoming much more aware of I'd say the greater world but she's also watching a lot of news…she's very aware of what's going on in and around the world and obviously it's a really frightening thing for any kid to be kind of looking at and watching." (P2, M)*

Adding to the sense that anxiety is outside of their control, parents also expressed a belief that their child was born anxious or ‘different’, that it is part of their personality and therefore cannot be managed or controlled:

> *“I think sometimes it is just how they are and it’s accepting of them in’t like you accept everybody for what they are.” (P9, M)*

> *“I hadn’t seen it as such a diagnosable issue maybe I thought it was you know either your child has these characteristics, or they don’t.” (P13, M)*

In a further nuance of this theme, parents spoke about their child’s inability to recognise their own anxiety and emotions, or the impact of their behaviour, which leaves parents feeling unable to manage or challenge their child’s behaviour:

> *“If you ask Hannah why is she feeling worried she doesn’t understand why she’s feeling worried.” (P11, M)*

In addition to the sense of helplessness over the factors causing and maintaining anxiety, parents also spoke about being powerless to help their child, feeling that there is nothing they can do, or that they have tried everything and do not know what else to do:

> *“As a parent, there’s nothing worse than thinking I’ve done everything I can, and I can’t help my child…yeah it got to the stage where I just burst into tears cos I couldn’t do anything for her.” (P11, M)*

> *“I don’t know what to do with her, I should know what to do with my own daughter, but I don’t.” (P15, F)*

Uncertainty and doubt

Parents’ sense of uncertainty about whether their child has an ‘anxiety disorder’ and feeling unsure about how best to manage their child’s difficulties is another important theme developed from participants’ responses, adding to the sense of ‘helplessness’ expressed by participants.

Throughout the interviews, parents discussed not knowing whether they should be concerned about their child’s behaviour and a process of trying to work out whether the anxiety and behaviours displayed by their child is within the realm of ‘normal’ behaviour. Parents’ expressed confusion about whether their child’s behaviour is part of ‘normal’ development or a ‘phase’ they are going through:

> *"…whether I'm just over reacting I guess because you know a mother cares about their child, am I just worrying a bit too much, is he just you know growing up, it's just normal or whatever normal is, or is just a phase." (P8, M)*

> *"I suspect that it's quite common for the younger ones to er have this…. I see it as part of growing up…err…you know the shyness." (P16, F)*

Peer dynamics were discussed as a source of distress for their child, often related to friendship issues and peer pressure experienced in the school environment. These issues may add to parents' sense that difficulties at school and with peers is a normal part of growing up, adding to the uncertainty and doubt about whether to be concerned:

> *"I think a lot of the anxiety was related to not achieving and self-confidence and things at school as well, and there were a certain couple of children that weren't particularly nice to her at school and she had friendship issues and that worried her…" (P3, M)*

Parents also discussed not recognising that their child was experiencing difficulties, or if they did notice difficulties, they felt unsure about what is wrong or why their child behaves in this way:

> *"she said that she really suffered you know back in year 5 and year 6…I don't think myself or my partner were aware of any of that, you know I think we just saw Emma as a bubbly confident, go getting character..." (P12, F)*

> *"We know something's not quite right with Billy, but we can't put our finger on it and that's probably frustrating for both of us you know." (P9, M)*

Parents also discussed uncertainty about how to understand their child's difficulties, and sometimes understood their child's behaviour as symptoms of other difficulties, such as Autism or Dyslexia:

> *"I was surprised that it was anxiety because it was just very behavioural and the repetitive questions and things like you know I didn't associate with anxiety at the time, I just thought it was more autistic you know the need to kind of repeat yourself over and over again." (P3, M)*

> *"I couldn't have said they were anxiety related or anything cos I couldn't tell then, I couldn't tell what the behaviours were generated by." (P10, M)*

Uncertainty and doubt were also apparent when participants discussed their lack of confidence describing and identifying anxiety in their child, qualifying their comments by mentioning their lack of experience with anxiety disorders and stating that they are not professionals:

> *"I'm not qualified I might add, but I personally don't think that there is a major issue." (P16, F)*

Parents also experience uncertainty and doubt about how to manage their child's difficulties, and a sense of not knowing whether their current ways of managing are helpful or could exacerbate the anxiety:

> *"…we're not very strong or we're still not really sure how to deal with it, so yesterday the melt down with my mum I ended up taking her home." (P13, M)*

> *"I wasn't also not entirely sure whether my child does suffer from anxiety, whether it's severe or whether it's just mild or whether she actually does need help or not, you know I'm still in between that - not really knowing if there's you know…anything I can do to help." (P5, M)*

Related to this sub-theme, parents discussed their uncertainty about whether to seek professional help, and a lack of knowledge about available support. This is not discussed in detail here, as this overlaps with a previous analysis (Reardon et al., 2017b).

2.3.2 Emotional and demanding

The second main theme developed from the interview data relates to the emotional impact of having a child with an anxiety disorder on parents. Participants discussed the difficult emotions experienced when parenting a child with an anxiety disorder, feeling isolated and alone, and spoke of feeling exhausted by the demands placed on them.

Emotional distress

Parents identified a range of emotions attached to their parenting experiences, including worry and concern about their child, feelings of anger and frustration, a sense of guilt and self-blame, and their sadness and grief about having a child with an anxiety disorder.

The worry and concern parents experienced was evident across interviews, and related to the impact on all areas of their children's life, including academic work, social relationships, stigma, physical health and enjoyment in life:

> *"I do think Sarah's academics have been hindered a lot by her anxiety." (P1, M)*

> *"I think it affects her with her friends because…they don't know how to react when she's anxious about something." (P11, M)*

Parents also expressed concern about the impact anxiety has on family relationships, including concern that their other children are adversely affected by their sibling's anxiety:

> *"Yeah she was becoming impossible and we had a three-year-old in the house at the time and it was the impact it was having on him and her older sister who's 13 at the time and you just kind of felt like it's not fair on them and so we need to do something about it." (P15, M)*

For parents where a child has self-harmed or has had suicidal thoughts there was additional worry related to the safety of their child:

> *"It affects everybody that's looking after Emma, she spends an awful lot of time at school and we need to make sure that's she's also going to be safe there as well." (P12, M)*

In addition to the concern about the current impact of anxiety, parents expressed their worries about their child's future. Parents fear that their child's anxiety will get worse, particularly during adolescence and in the transition to senior school. Parents also had concerns about the longer-term influence of anxiety, that their child would not reach their 'full potential', or that they would experience difficulties in later life:

> *"I think she might have the ability to do certain things, you know anything in life, but her fear and anxiety is keeping her from reaching that potential." (P5, M)*

> *"I do worry the more stressful situations are going to be put under which she will as she gets older at school and everything else is how she is going to manage." (P14, M)*

Some parents did not experience concern about anxiety, seeing this as 'normal', or feeling assured that their child would overcome the anxiety:

> *"I don't think it's anything that's impacted her development, I think it may have slowed it down initially but she's coming along, she'll be alright." (P16, F)*

In addition to experiencing worry and concern about their child, parents also shared that they can become angry and frustrated by their child's behaviour. These feelings seem to be fuelled by the lack of clarity about whether anxiety is driving the behaviour, or whether their child is behaving like this to get attention:

> *"To be honest in other situations yes I do get angry with her because it seems she, you know with work and other things, she does it's this constant "I can't do this on my own, I need you to help" and "I don't understand", and she'll talk over me when I'm trying to help explain things to her, and I do get angry." (P14, M)*

Parents described their own emotional distress about seeing their child suffer. Parents used emotive language to capture their feelings, describing their experiences as 'devastating', 'soul destroying' and 'heart-breaking':

> *"There were just a few mornings where she was just extreme, and I just couldn't get her to stop having a tantrum and screaming and screaming and then it's just you know it's soul destroying as a parent having a child like that, I just, it was making our lives miserable." (P3, M)*

Related to this, parents allude to the grief and loss experienced. They refer to their child as having changed as a result of anxiety:

> *"Before that she was a child that nothing worried her, nothing frightened her, she was just you know she'd stand up for herself…but since then we've just noticed a complete change." (P11, M)*

> *"…you're so far down the line that you know things have changed so much, we all think we want Emma back, but Emma isn't going to be Emma anymore, she's a new Emma and we need to learn to respect who she is and let her grow and let her express herself." (P12, M)*

Parents also discussed feelings of guilt and self-blame – that they didn't recognise anxiety earlier, or that they were too busy to focus on anxiety, or that it may be their fault that their child has an anxiety disorder:

> *"…you feel a failure as a parent that you've got to this situation and people are judging you and that is a big thing." (P9, M)*

Exhausting & draining

A further theme related to the meta-theme 'emotional & demanding' picks up on the exhaustion experienced when parenting a child with an anxiety disorder. Participants spoke about the difficulty of managing their child's challenging behaviour, including their child's anger and aggression, being clingy in new environments, needing to be in control, asking repetitive questions, seeking reassurance, and their child being on an *'emotional rollercoaster' (P12, M)*:

> *"I used to come home from work he was horrific, really angry at me for going to work and he would scream and shout and target me and try and bite and all of that." (P9, M)*

> *"At home, we have to be careful what we say to Hannah when she is anxious about something, cos to us it might not be anything at all but to her it might feel like it's something really big…she feels like we don't listen to her so sometimes it's a bit like treading on egg shells." (P11, M)*

In addition to managing challenging behaviour, parents expressed that their child's anxiety adds extra pressure to family life and was something else they now needed to manage**.** Anxiety was described as interfering with normal family functioning, such as getting children to school, interfering with the child's bedtime, and your child not wanting to do their homework. Anxiety was also described as *'getting in the way of family life' (P3, M),* impacting on family outings, sibling relationships and on parents' martial relationship, for example by parents having no time together in the evening *(P7, M)*:

> *"I do try to talk well yeah I have done but she almost switches it on at the most inappropriate moments in terms of trying to get out of the door to go to school, trying to go out to do work, or something like that, and actually it all comes up right at the eleventh hour." (P2, M)*

Parents describe being exhausted and at the end of their *'tether' (P9, M)* from trying to manage everyday life as well as their child's anxiety symptoms:

> *"I went and saw the GP and I basically broke down and said someone somewhere has got to help me because I can't keep on doing this." (P6, M)*

Isolated & alone

A final theme related to the emotional demands experienced by parents refers to feeling isolated and alone. Parents discussed feeling blamed by others, leading them to withdraw from others and a reluctance to seek support, adding to parents' feelings of isolation. Parents spoke about their experiences of being labelled as an anxious or incompetent parent, and a perception that being offered a parenting course reinforces this sense of parental-blame:

> *"There's a lot of assumptions that it's to do with my parenting, there seems to be a lot of "oh well you know it's obviously you're not parenting her in the right way", yeah there was a lot of offering of various parenting courses." (P1, M)*

> *"Yeah it's really hard going to constantly be told "no", or the problem is me and not anything else, it's really tough going." (P6, M)*

Parents also discussed the stigma attached to mental health difficulties, and that this may be especially prevalent with children and young people as this is a little understood area:

> *"Well I just think it is viewed as a weakness, it's a bit like depression you know, it's a mental health issue, and it doesn't matter how you dress it up, or you know all the campaigns or whatever, it will always be viewed as a weakness." (P2, M)*

> *"Oh yeah, because they're children, they're not meant to have illnesses, or you know especially mental illness is still quite you know it's…err…unknown." (P8, M)*

Parents therefore expressed concern about making things worse for their child if they seek support for themselves and/or for their child's difficulties. Related to this, parents discussed that they did not want to talk to others about their child's anxiety:

> *"To be honest it's not the kind of thing you want to talk about with your friends, you know being honest with you…because it's an admission of failure that you haven't been able to deal with it yourself." (P15, M)*

Increasing this sense of isolation, a common thread running through the interviews was a concern that because their child only behaves like this when at home/with their parent(s), others may not believe their child has anxiety, leaving parents feeling more isolated:

> *"I just knew that the minute that she walked into school she would be fine, cos she never does it, it is just all put on for me she doesn't behave like that at school in front of her teachers." (P3, M)*

> *"Yeah, when there's a two side issues so there's angelic behaviour and you know the opposite behaviour it's very hard to manage and you're describing this child and then the angel turns up that also is hard, that you know sets you out feeling that people won't believe you." (P10, M)*

Parents also discussed feeling like they are battling on their own due to the lack of information and support available from professional services. This is not discussed here in detail, as this was not the focus of the current study and significantly overlaps with the primary qualitative analysis conducted by Reardon et al. (2017b).

2.3.3 Hard work and effort

Despite the feeling of helplessness and the emotional demands placed on them, parents consistently spoke about working hard to support their child. Parents describe an ongoing process of trying to find out as much information as possible to make sense of their child's difficulties, working hard to manage anxiety, and trying their best to help their child.

Making sense of anxiety

In order to better understand their child's difficulties, parents took an active role of trying to learn more about the nature of anxiety and wanting to know more about what they could do to help their child:

> *"Just to help know what to do I think that's an ongoing battle with me, just oh what can I do in this situation, what is the best thing to do, how is this going to help you know, and yes I've got a few tools now, but I could do with a whole load more in various situations." (P13, M)*

Parents used various strategies, to varying degrees, to develop this understanding, including reading books and going online to access information, joining online forums and support groups, and going on courses related to mental health and anxiety. Through this process participants described developing a better understanding over time about their child's anxiety and ways to support them:

> "S*lowly you realise oh my gosh so there is something available in the schools or some of the schools and you know you begin so I'm sure there's probably more and I'm just not aware yet [laugh] I don't know maybe not [laugh]." (P13, M)*

Parents also spoke about drawing on their own experiences of anxiety to try to understand what their child is experiencing and to know how to help:

> *"Well apart from me trying my really my best trying to but you know but I do realise I'm not a professional, I'm just a mum and you know and I have to delve very much into my own experiences and then talking to my friends." (P5, M)*

> *"I said to Daniel about sort of when you sort get worried deep breaths and letting it out and counting to ten the things sort of I'd been told when I'd had panic attacks and things in the past." (P4, M)*

Parents spoke extensively about talking to others who may have experience, including friends, family, other parents and colleagues, to find out how to support their child:

> *"I think it's important to have other people's opinion on certain things rather than just worrying about it and not knowing what to do about it." (P14, M)*

Finding ways to manage

As well as working hard to learn about the nature of anxiety and how best to support their child, parents also discussed their experiences of trying to manage their child's difficulties. Parents spoke about the different issues they needed to manage, in addition to the symptoms associated with anxiety, including keeping their child safe in different environments, liaising with school about concerns and issues, managing the dynamics between siblings, and handling issues related to social media. Parents described the vast number of strategies and approaches they had tried to support their child, and the effort put in to find the best way to help:

> *"Yeah well we tried reading and stuff, but then we tried doing the other bits as well, but Daniel wasn't very keen on doing any of that, so whether it actually helped I'm not sure but that was the sort of thing we tried so erm yeah." (P4, M)*

> *"I just thought that it might be something cos she's quite arty, she likes writing stuff down and it might give her something to do rather than trying to talk to people because with Hannah it's easier to write a note or draw a picture than it is to actually speak about what's she's thinking." (P11, M)*

Parents spoke about the importance of showing love and support for their child, of having a close and trusting relationship and of talking openly about issues, where '*no subject that's taboo' (P16 F)*:

> *"He would scream and shout and target me and try and bite and all of that, and I just used to hold him and tell him I loved him, and it would be alright." (P9, M)*

> "*I try and give her some time and then I know that's the cue to start talking to her asking her questions when she's calmed down and realising ok you know something's happened or there's something else she's feeling nervous about." (P5, M)*

Parents used various other approaches in an attempt to support their child, including anticipating issues and planning in advance, employing a private tutor to provide academic support, reading and talking about anxiety with their child, finding activities to develop their child's confidence, teaching breathing techniques, a using visual timetable and stress toys. Parents also discussed seeking professional help, which was beyond the scope of the current study and overlaps with the analysis by Reardon et al. (2017b).

Parents also discussed the need to adapt family life to cope with and work around the anxiety:

> *"We change, we all change completely the way that something is done so she doesn't get anxious." (P1, M)*

> *"It was just about trying to get him through the day, you know, we didn't do quite so much support with his homework and reading because he just couldn't deal with it." (P9, M)*

Parents discussed various ways that they would accommodate anxiety, by facilitating avoidance, giving reassurance, and even giving their child medication unnecessarily to ease their child's anxiety about being ill. Parents were often able to recognise that they can get into unhelpful patterns, but felt powerless to stop this:

> *"I still had to phone in advance if we went anywhere and say, "In your toilet do you have a hand dryer?" because if he went in the toilet cubicle and the hand dryer was in the toilet cubicle he wouldn't go in the toilet cubicle." (P10, M)*

> *"It becomes almost like it's difficult to break this pattern as well because he's just at the end he felt it was just normal for [husband's name] or me to sleep in the same room, which wasn't ideal." (P7, M)*

> *"I just thought it's too much for her I'll take her home [laugh] and whether I'm feeding it I don't know, but it's just it didn't seem worth the upset." (P13, M)*

Parents described their approach as reactive, rather than a planned response to their child's difficulties, with parents trying to find the best way to cope:

> *"…from day to day you just carry on." (P7, M)*

> *"It was just disaster management I think really for Billy, it was just about getting through the day." (P9, M)*

Parents also expressed the importance of managing their child's difficulties themselves, or as a family. This links to the theme of isolation (discussed above), but the focus here is on parents emphasising that this is part of their parental role and responsibility, rather than specifically talking about not seeking help because of stigma:

> *"It's part of his life, part of our life, we need to we need to support him here first and take it take it as a family basically." (P7, M)*

Parents also spoke about the importance of liaising with teachers, health professionals and other parents in order to support their child. For some parents, managing their child's anxiety involves liaising with the school, to talk about seating arrangements in the classroom or their child's class allocation for example, but also involves communicating with teachers about their child's current difficulties:

> *"We've involved the school if there's been a problem, or we've thought there was a problem, and the school's been great." (P16, F)*

This has also involved difficult interaction with the school when things have not necessarily worked out well (complaint letter P11), feeling like your child is being unfairly treated at school, or that the school is not taking your child seriously. One parent also discussed involving other parents in order to support her child, as she felt other children were unfairly targeting her child:

> *"I witnessed a couple of instances in the playground when we arrived in the morning and it wasn't all Billy, you know, and I had to speak to a couple of parents." (P9, M)*

Trying my best

A further theme connected to hard work and persistence relates to parents' experiences of doing their best, by trying everything possible to manage their child's anxiety, as well as seeking out ideas about how else to support their child, which is also evident in the amount of anxiety management strategies and techniques discussed above:

> *"Yeah cos I'd looked up online to see if it was something that you know we could help and we'd done most things that we could do here, which was put things on to stop her from pulling it, give her stress toys so she'd have something to play with rather than to pull, erm and all the other recommendations." (P11, M)*

> *"I feel a little bit better that I have done the best that I can right now for Billy, and for all of us, whether anything has come of that or not so be it." (P9, M)*

> *"Well, apart from me trying my really my best, trying to, but you know but I do realise I'm not a professional I'm just a I'm just a mum." (P5, M)*

Throughout the interviews parents also spoke about the need to protect their child from potentially anxiety-provoking situations and knowledge, and how it can be difficult to find the right balance between protecting your child, without having a detrimental effect:

> *"I'm really reluctant to allow her that kind of access into the social side you know social media, but at the same time it seems to be what eighty percent of the kids are doing, so what do you do? It's a real fine balance, you've gotta because otherwise you become a bit of an outcast because they're not in with everyone else." (P2, M)*

Parents' protective role also extends to not wanting to upset their child. For some, this was about not talking about their child's difficulties in front of them, and also hiding the impact these difficulties have on them as parents and the rest of the family:

> *"I'm not taking her with me (to see the GP) because I don't think it's fair on her to keep saying all these negatives about her in front of her, she's got low enough self-esteem." (P6, M)*

> *"At the same time trying to be the parent, you know, who is boundaried with a child who can't cope with boundaries, erm and trying to be that positive person at the same time, you know, so you know "everything is fine darling, everything's fine" you know, and they can sense it isn't, but what else can you do?" (P10, M)*

This focus on protecting their child can sometimes lead to parents accommodating, rather than challenging, anxiety:

> *"Yeah but I you know I wouldn't want him to be upset so I kind of try to do my best and make sure that he's not but then perhaps sometimes perhaps I should say to him you know you're doing it or you you're going to bed now I'm going downstairs so yeah." (P4, M)*

2.3.4 Hopefulness and progression

Alongside the themes of helplessness, emotional turmoil and hard work, the final theme developed from the interview material relates to the sense of hope and positivity experienced when parenting a child with an anxiety disorder.

Anticipating/experiencing progression

Some parents talk about anticipating or actually experiencing their child's anxiety and behaviour improving. Parents speak about the hope experienced when they realise that anxiety disorders can improve:

> *"It was helpful to me to realise that this is you know something I do need to address, it's not just her character, or it might be in her character, but…it's not just something I need to accept is the case, I can help it." (P13, M)*

Parents also speak about noticing that their child's anxiety and behaviour has improved:

> *"We have come a long way you know it's certainly it's not as bad as it was in year 1 as I am now at year 4 you know Billy is recognising his warning signs and Billy is accepting the fact that it's not acceptable to do hitting or kicking and you know, but it's taken us three good years to get to where we are today." (P9, M)*

This sense of hope also stems from parents' own experience of anxiety, and knowing that anxiety is something that you can learn to manage:

> *"I know that sometimes when Sara says like "oh my friends don't like me" or "I feel I'm not good enough" and I had these things from time to time when I was young, and I got over it, but I can't remember how I got over it [laugh]." (P16, M)*

Connecting with others

A further thread running through the interviews is the importance of connecting with others, and how this contributes to the sense of hopefulness experienced by some parents. Parents discussed seeking advice and support from others with experience about how to manage anxiety, as also mentioned in the theme relating to 'learning more about anxiety'.

> *"My best friend has four of her own children and so she's got loads of experience [laugh] erm yeah so I forever I always ask her for advice and then she's quite er you know whatever advice she's given me works quite well." (P5, M)*

Speaking to other parents facilitates an understanding of their child's anxiety, for example by finding out about peer dynamics and what is 'normal' behaviour for children of this age.

> *"It just seems there's probably quite a few….it seems that each child is experiencing something of a similar nature if you like." (P3, M*)

Parents also discuss gaining support from other parents, which not only helps them to understand their child's anxiety but also gives them a sense of being understood:

> *"I'd say the most help I've got is from the facebook pages when you're really down at two in the morning and you just cannot get up the next morning and do it again, er other facebook users are also up at two in the morning and they're just going "I'm here, I'm awake and you're not on your own"." (P10, M)*

> *"There have been several times when…I've gone to the chat group and gone [shouting] "Oh my god" and had a rant about what's happened, and they've gone "Actually, you know what that's perfectly normal, we have this too, it's like that in our house", which is really nice to hear that I'm actually not on my own and they're not turning round and going "well actually it's your parenting", which is all I seem to get from professionals." (P6, M)*

Parents can find it particularly difficult if their support network is taken away. One mother discusses how her child's school provided her with a lot of support in managing her child's difficulties, and so when her child was excluded from the school, she also experienced a sense of isolation from those who were previously supporting her. Similarly, one parent discussed that the issue of diagnosis can also determine which support groups you can/cannot gain access to:

> *"I lost everything when I lost that school [crying] because I lost daily contact twice a day with absolutely solid people who were there for me, and I lost a community and I lost everything yeah [crying] when we had to leave there." (P10, M)*

One parent also discusses that having a child with an anxiety disorder facilitated the development of a friendship with a neighbour, whose child also experiences mental health difficulties:

> *"I wish I'd kind of popped round my neighbours 12 years ago [laugh]…I say "hello" to her every single morning, "alright, how are you?", "Yep, fine, lovely", I've been doing that for 12 years not knowing all the stuff that's going on behind the scenes". (P12, M)*

Two parents also discussed that their own experiences of parenting a child with an anxiety disorder has provided them with the aspiration, knowledge and skills to be able to support others:

> "*I sometimes have parents who ask me for advice, and sometimes I need a little bit of advice, so you know we help one another really yeah." (P5, M)*

> *"I've also now started training now for myself erm for the [county name] county council to mentor, they've got a volunteers' programme running at the moment."* (P13, M)

2.4 Discussion

Interviews were conducted with parents (the majority of whom were mothers) of 16 children, aged 7-11 years, with anxiety disorders identified in the community. The aim of this study was to explore participants' experiences of parenting these children. As illustrated in Figure 3 (Thematic map), four main themes were developed from the data: 'Helplessness', 'Emotional & demanding', 'Hard work & effort' and 'Hopefulness & progression'. In this section, the main findings will be reviewed in relation to previous literature, and consideration will be given to the clinical implications of this study and the identification of areas for future research based on the findings.

2.4.1 Interpretation of key findings

Helplessness

Firstly, parents discussed experiences of feeling 'helpless' in the face of their child's anxiety disorder, perceiving that the factors causing, or exacerbating anxiety are beyond their control, and uncertainty surrounding the identification of difficulties and how best to support their child. This theme supports the findings of previous studies in this area. Parents of young people with a range of mental health problems have reported a lack of understanding about their child's presentation (Cottee-Lane et al., 2004; McDonald et al., 2007), difficulty identifying a mental health problem (Stapley et al., 2015), and uncertainty about how to manage symptoms (Futh et al., 2012). A recent systematic review of parent-perceived barriers to accessing mental health services for children and adolescents also found that parents report difficulties identifying that their child has a mental health problem, and a lack of knowledge about how or where to seek help (Reardon et al., 2017a). Parents in this study spoke about not knowing whether their child is experiencing anxiety or other difficulties, which is understandable given that many children with an anxiety disorder experience co-morbidity with depression and behavioural disorders (Lewinsohn et al., 1997).

Parents in this study also expressed feeling helpless to change their child's anxiety and associated behaviour, perceiving this to be linked to their personality. This has not been alluded to in previous research, perhaps indicating that this may be specific to anxiety disorders. This finding is interesting to consider in relation to the growing field of research suggesting that some children are born with higher levels of 'behavioural inhibition'; these children are more vulnerable to developing anxiety disorders, particularly social anxiety disorder (Hirshfeld-Becker et al., 2007).

This research is consistent with parents' experiences that their child's difficulties with anxiety start early in life and that they are 'born' more sensitive.

Emotional & demanding

The second main theme developed in this study, 'emotional & demanding', also reflects findings from previous qualitative research in this field, which emphasise the emotional distress (Cottee-Lane et al., 2004; Futh et al., 2012; McDonald et al., 2007; Stapely et al., 2015), sense of isolation (Stapley et al., 2015), and the extra demands and exhaustion (Knock et al., 201; Maskill et al., 2010; McCann et al. 2011; Reardon et al., 2017a; Stapley et al., 2015) experienced when parenting a child with a mental health difficulty. In a longitudinal research project with 64 families, Early et al. (2002) found that child functioning significantly impacts parental well-being, and child functioning worsens with lower levels of parental well-being. Understanding the impact of parenting an anxious child is therefore important, not only to know how to better support parents, but also to improve outcomes in children.

The sense of isolation experienced by parents is exacerbated by feelings of blame and fear of stigma, which prevent parents from speaking to others or seeking support. Parents in this study particularly refer to feelings of guilt, blaming themselves for their child's difficulties. Hoskins & Lam (2003) refer to the 'identity of dysfunction' parents, particularly mothers, can adopt in relation to their child's mental health difficulties. Parents also reported feeling blamed and criticised by professionals, and fear being stigmatised, all of which have been found in previous research to prevent parents from accessing help and support for their children when they are experiencing mental health difficulties (Reardon et al., 2017a). The BPS (2015) also emphasise that difficulty recognising mental health difficulties and fear of stigma are important factors preventing children and young people from accessing help.

Parents' narratives in this study particularly focus on distinguishing whether their child's behaviour is 'normal', or whether their child has a mental health problem. Although this has also been reported in previous findings (Futh et al., 2012; McDonald et al., 2007), this process may be particularly pertinent to anxiety disorders due to the continuum of the disorder (Stein et al., 2010). Biddle et al. (2007) propose that this on-going process of 'normalising' mental health difficulties is a strategy used to avoid help-seeking, which is perceived as threatening due to the negative social meanings attributed to illness and being helped. Indeed, parents refer to the fear of stigma (within the theme 'isolated and alone'), and so targeting stigmatising attitudes towards parents and parental 'blame' could also facilitate recognition and increase access to professional support (BPS, 2015; Reardon et al., 2017a).

Hard work & effort

In stark contrast to parent's feelings of helplessness, parents spoke in detail about how hard they work to understand and manage their child's anxiety. This theme has been less reported in previous literature, although Stapley et al. (2015) describe 'parenting in overdrive' when adolescents are diagnosed with depression, referring to the adaptations and changes made to manage their child's difficulties, and 'trying everything' to help their child. Previous findings also indicate that parents manage uncertainty about their child's mental health by actively trying to understand their child's presentation (Cottee-Lane et al., 2004; Futh et al., 2012; McDonald et al., 2007); also reflected in the current study.

It is possible that the emphasis parents place on their hard work and effort may be influenced by the nature of the current research study, where most parents have not yet accessed mental health services and the research team are able to facilitate this support.

Parents in this study also spoke about the importance of managing their child's difficulties by themselves or with the support of family, also reported in previous research (Stapley et al., 2015). In a recent systematic review (Reardon et al., 2017a) parents also emphasised the importance of solving problems within the family rather than accessing professional support.

In an effort to meet their child's needs and to protect their child, parents described adapting their parenting to meet their child's needs. This is in line with previous research indicating that parenting strategies thought to increase anxiety in children and adolescents, such as parental over-protection and control (Rapee, 2012), should be understood as reciprocal, with parents adjusting their parenting style if their child is more anxious (Creswell et al., 2015). In an attempt to support their child, parents described strategies that may inadvertently exacerbate their child's anxiety; for example, by providing reassurance and facilitating safety behaviour. Parents emphasise that they are doing the best they can, but this is within the context of a lack of information about how best to support their child. Clinicians therefore play an important role in supporting parents and providing information about psychologically-informed approaches to managing anxiety disorders.

Hopefulness

A final theme running through parents' accounts relates to a sense of hope and progress. This theme is less frequently represented in the data but was a consistent theme throughout the interviews. Parents spoke about seeing improvements in their child's anxiety or feeling hopeful about the future. This theme is not currently represented in previous research, perhaps because this is a community sample rather than a clinical sample, and so children may be exhibiting less extreme difficulties. In addition, anxiety is seen to overlap with ‘normal’ behaviour, and so parents may recognise the continuous nature of the disorder.

The hopefulness experienced by parents also relates to parents’ reflections that their child’s difficulties had facilitated connection to others; this connection decreases isolation, with others supporting parents to identify and manage anxiety. The importance of these social relationships is discussed throughout the interviews, and links with the other themes; this is a key way that parents manage the difficulties faced. This finding is supported by the help-seeking literature, which consistently indicates that parents would rather seek help informally through social networks than access professional help (see for example, Rickwood et al., 2015). It is not clear whether informal support increases access to mental health services, with research supporting this as both a barrier and facilitator to professional help-seeking (Reardon et al., 2017a).

2.4.2 Clinical implications

This study highlights a number of implications for clinical practice.

Firstly, it is clear from parents’ accounts that they experience difficulties identifying and knowing how to manage anxiety disorders in their children. It is therefore important to increase public awareness about anxiety disorders in childhood, and provide professionals working with children with the knowledge and tools to help identify mental health problems and raise awareness of available support (BPS, 2015; Reardon et al., 2017a). Health professionals and teachers have an important role in signposting parents to useful resources and to provide psychologically-informed support about how best to manage difficulties at home, for example by signposting parents to online resources such as ‘MindEd’, which aims to increase awareness of childhood mental health among professionals and families (BPS, 2015).

Second, given the emotional demands experienced by parents, it is important to address the potential impact on parents’ own well-being. It may be particularly helpful for professionals to validate and normalise the difficulties experienced by parents, for example by developing and sharing information relating to ‘typical parenting experiences’. Furthermore, parents may benefit from professional support to manage their own distress associated with their child’s difficulties, potentially through psychological therapy in their own right (Marsh & Johnson, 1997). In addition to the impact on parents, the findings from this study emphasise that the whole family can be affected by childhood anxiety disorder. In treatment approaches it is therefore important to consider the whole family, rather than focusing only on symptom management, by using systemic approaches to address the changes in roles and responsibilities (Francis, 2012), for example. A systemic approach may also be useful to explore and consider the social discourses surrounding the ‘mother-blame’, where mothers, in particular, are seen as being solely responsible by society for their child’s behaviour and development (Blum, 2007).

Thirdly, parents can feel blamed and judged by others when their child has a mental health difficulty. It is especially important, therefore, that professionals working with children and families do not add to the stigma and blame experienced by these parents. Mothers may be especially sensitive to this; cultural discourses position mothers as being to blame when young people fall outside the norms of ‘acceptable’ behaviour (Jackson and Mannix, 2004). The BPS (2015) emphasise that parental concern is often labelled as anxiety. Feeling blamed or misunderstood by professionals is likely to prevent help-seeking. It is important, then, for parents to feel listened to and their concerns taken seriously by all professionals working with children and young people, in line with the culture of ‘no wrong door for help’ (Department of Health, 2015).

Fourth, in this study parents spoke about valuing support received from others. Overcoming barriers that prevent social connection is therefore important. Professionals can encourage the use of support networks by normalising parents’ concerns and difficulties, and signposting to appropriate support networks. Increasing the availability of support groups for parents who have children with mental health difficulties may be particularly useful to help parents manage their own distress and generate ideas to support their child, thereby improving outcomes for young people. Given the similarity between findings from this study and parental experiences with other mental health difficulties, support groups may be effective if delivered in a mixed-group format (Stapley et al., 2016).

Finally, parents discussed the wealth of strategies and techniques used to manage their child’s difficulties. With limited NHS resources available, more parents are likely to be managing their child’s difficulties at home. It may therefore be helpful for schools and health services to validate what parents are already doing. Using solution-focused approaches rather than problem-saturated narratives may help to increase parental confidence in managing their child’s difficulties; whilst also signposting parents when necessary to more psychologically-informed approaches to managing anxiety.

2.4.3 Strengths and limitations of the current study

This study has a number of strengths. Previous research has mainly focused on clinical populations; by using a sample of children and parents identified in the community, this study was able to access the views and experiences of families who had not necessarily sought help for their child's anxiety disorder. As the majority of young people with anxiety disorders do not seek help, this is likely to be a more representative sample of parents than that obtained using a clinical sample. The purposive sampling approach used also ensured that families included in the study had a varied demographic profile and were from different geographic regions in England. Treatment access is particularly low among children, and so the focus of this study specifically on anxiety disorders among children aged 7-11 years provides insight into parent's experiences among this population, which may be particularly useful to know in order to better support these parents. In addition, the size of the sample facilitated the collection of rich data. Despite this being a secondary analysis, a large number of initial codes were developed relating to the secondary research question, highlighting the importance of capturing participants' narratives about their experiences. The analytic process was strengthened by the involvement of a wider research team to discuss and reflect on the codes and themes from the material. In addition, an audit trail was developed to increase the transparency of the analysis (Yardley, 2015).

It is also important to note the following limitations. The majority of children included in the study were female, and so it is not clear to what extent the findings of this study transfer to parents of males. Furthermore, as most interview participants were mothers, limited information can be gleaned about fathers' perspectives. This is in line with previous qualitative research in this field (Stapley et al., 2015), but again this limits the extent to which conclusions can be drawn about fathers' experiences. It is likely that parents with concerns about their child's anxiety or mental health were more likely to participate in this study, introducing a participation bias. Many families invited to participate in each stage of the process did not engage, suggesting that parents who were not aware that their child may have an anxiety disorder or parents who may not be comfortable engaging in research, for example, if English is not their first language, may not have been included in this study. Again, this limits the generalisation of the elicited perspectives to a wide range of families. Parents were invited to interview based on their child meeting a diagnostic threshold for anxiety disorder, using the SCAS. However, the SCAS has not yet been established as a reliable tool to identify children with clinically significant levels of anxiety and so it is possible that not all parents of children who have anxiety disorders were identified (i.e. the child scored below the cut-off score on the SCAS-P, SCAS-C and SCAS-T).

As this study is a secondary analysis of interview material, a further limitation involves the purpose of the original interviews. Interviews were set up to focus on parents' experiences of help-seeking; therefore more detail may have been captured if the interviews were more generally focused on experiences of parenting a child with an anxiety disorder. The advantage of this approach is that parents may have been less guarded about reflecting on their own experiences, but the interviewer was not able to explore areas of interest related to the current research question, limiting the scope of the current analysis. In addition, ongoing data collection and analysis could not take place, and so it was not possible to identify interesting themes and develop this through the use of theoretical sampling (Pidgeon, 1996). The research question for this secondary analysis intentionally had a wide focus; further research in this area may benefit from narrowing this focus and exploring particular areas of experience in more depth (for example, the emotional demands of parenting a child with an anxiety disorder).

Finally, it is important to consider the role of the interviewer and purpose of the interview. Parents' awareness that the interviewer had a psychology background and worked as part of a research team focused on anxiety is likely to have placed parents into a more powerless position, with the interviewer/research team positioned as knowledgeable and 'expert'. Some parents explicitly mention that they chose to get involved in the research as it may help them to access mental health services, and so parents may have been more likely to use language to reflect their sense of helplessness in order to elicit more support, or perhaps because there is an unwritten expectation that medical support is needed to treat anxiety disorders.

Despite the limitations, this study importantly contributes to the current evidence base about the challenges experienced by parents when a child has an anxiety disorder, as well as some of the ways parents find to manage these difficulties. Areas for future research are discussed below.

2.4.4 Directions for future research

To expand on the current study, it would be useful to gain more insight into fathers' experiences, and to establish joint parenting practices used in the management of childhood anxiety disorders. In addition, it is important to find creative ways to access the views and perspectives of parents unlikely to engage in this type of research project, particularly those from under-privileged areas. Finally, this research was a secondary data analysis and as such the main focus of the interviews was not on parents' experiences. It would therefore be useful to develop a research study which focuses specifically on this area, to allow for more in-depth exploration of the support parents themselves feel would be beneficial when managing their child's difficulties at home.

2.4.5 Conclusions

This study has focused on the experiences of parents of children with a diagnosis of anxiety disorder, drawn from a community sample in the UK. The findings of this study are in line with previous qualitative research in this area, which show that parents experience difficulty identifying that their child has an anxiety disorder and feel uncertain about whether their child needs help for their difficulties, or how best to support their child. Parenting a child with an anxiety disorder is exhausting and emotionally draining, and parents can feel that they are managing these difficulties by themselves. Despite these challenges, parents are resourceful and work hard to understand and manage their child’s difficulties and feel hopeful about their child’s progress and the support provided by their social network.

Appendices

Appendix A1: Search terms

- Search Title / Abstract; limits: English, Article
- Group 1 AND Group 2 AND Group 3 AND Group 4

Table A1. *List of search terms used in databases.*

Group 1	Group 2	Group 3	Group 4
Barrier*	Help-seeking	Mental*	Child*
Hurdle	help seeking	disorder*	Adolescen*
Obstruct*	helpseek*	Psychopathology	Youth
Obstacle	‘Seek* help’	‘Emotional problems’	Parent*
Promot*	‘Care seeking’	‘Emotional distress’	Caregiver*
Facilitat*	‘seek* care’	‘Behavio* problems’	Carer*
Encourage*	‘access treatment’	Internali*	Teen*
Support*	‘access service’	Anxi*	Mother*
Cause*	‘seek* treatment’	Affect*	Father*
Predict*	‘Service* use’	Depress*	Maternal
‘Unmet need’	‘Service* utilisation’	Suicid*	Paternal
Hinder	‘Service* utilization’	Externali*	
Willingness	‘treatment participation’	ADHD	
Enable*	‘treatment engagement’	‘self harm’	
		Psychosis	
		Oppositional	
		Conduct	

Appendix A2: Inclusion and exclusion criteria

Inclusion criteria

1. Participants were children and adolescents up to and including the age of 18 years. Studies were excluded if the mean age of participants was over 18 years, or if the sample included any participants over the age of 21 years.

2. Study reported children's and/or adolescents' perceived barriers or facilitators to accessing psychological treatment for mental health problems. Studies reporting only parental perspectives of barriers/facilitators were excluded.

3. Study published in English in a peer reviewed journal.

Exclusion criteria

1. Study did not report barriers or facilitators to accessing treatment for mental health problems in children/adolescents

2. Study was a review.

3. Study was not published in a peer-reviewed journal.

4. Study only reported parent perceived barriers or facilitators to accessing treatment for mental health problems

5. Study only reported factors associated with or predictors of parent or child/adolescent help seeking behaviour / service use / help seeking intentions

6. Study only reported findings from an intervention designed to address one or more barrier to help-seeking

7. Study only reported barriers/facilitators to accessing ongoing to treatment, not initial access to treatment

8. Study only reported barriers/facilitators to accessing treatment for autism spectrum disorder or developmental disabilities

9. Participants in the study were not children or adolescents (excluded if the mean age of the children/adolescents was >18 years or if the sample included adults >21 years)

10. Study did not report any qualitative or quantitative data that could be extracted.

11. Study only reported barriers/facilitators to accessing medication or inpatient psychiatric care.

12. Participants in the study represented a special population (ie, children/adolescents with an intellectual or developmental disability, young offenders, children/adolescents with mental health problems in the context of a specific physical health condition, looked after children)

Notes

Study must report child/adolescent perceptions of barriers ie, questionnaire / scale framed as ‘barriers’ (or reasons not to seek/access help).

Not include studies that only report child/adolescent attitudes/expectations/beliefs, if not reported specifically as a barrier or reason to help/hinder help-seeking or treatment access (e.g. not include if only report measure of stigma, trust, if child/adolescent not asked to rate as a barrier).

Appendix A3: Modified version of the criteria developed by Kmet, Lee and Cook (2004) for use with qualitative studies

Table A2. *Adapted quality assessment tool for qualitative paper.*

	Yes	**partial**	**no**
Question/objective sufficiently described	Research question or objective is clear by the end of the research process	Research question or objective is vaguely/incompletely reported	Question or objective is not reported, or is incomprehensible.
Are the research question/s suited to qualitative inquiry	Research question/s suited to qualitative inquiry	Research question/s may be suited to qualitative inquiry, but question/objective too vague or incomplete so not possible to assess fully	Research question/s not appropriate for qualitative inquiry
Study design well described and appropriate	Design is easily identified and is appropriate to address the study question	Design is not clearly identified, but gross inappropriateness is not evident; or design is easily identified but a different method would have been more appropriate.	Design used is not appropriate to the study question; or design cannot be identified.
Context of study clear	The context/setting is adequately described, permitting the reader to relate the findings to other settings	The context/setting is partially described.	The context/setting is not described
Sampling strategy described, appropriate and justified	The sampling strategy is clearly described and justified. The sample includes the full range of relevant, possible cases/settings (i.e., more than simple convenience sampling), permitting conceptual (rather than statistical) generalizations (e.g. purposive sampling).	The sampling strategy is not completely described, or is not fully justified. Or the sample does not include the full range of relevant, possible cases/settings (i.e., includes a convenience sample only).	Sampling strategy is not described.

	Yes	**partial**	**no**
Data collection methods systematic, clearly described and appropriate for research question	The data collection procedures are systematic, and clearly described, permitting an "audit trail" such that the procedures could be replicated; and appropriate for research question	Data collection procedures are not clearly described; difficult to determine if systematic or replicable. Or procedures clearly described but alternative method would have been more appropriate for the research question.	Data collection procedures are not described.
Data analysis systematic, clearly described and appropriate for research question	Systematic analytic methods are clearly described, permitting an "audit trail" such that the procedures could be replicated; and appropriate for the research question. The iteration between the data and the explanations for the data clear – it is apparent how early, simple classifications evolved into more sophisticated coding structures which then evolved into clearly defined concepts/explanations for the data. Sufficient data is provided to allow the reader to judge whether the interpretation offered is adequately supported by the data	Analytic methods are not fully described or an alternative methods would have been more appropriate for the research question. Or the iterative link between data and explanations for the data is not clear.	The analytic methods are not described. Or there is no evidence of any iterative process involved in the analysis.
Use of verification procedures to establish credibility	One or more verification procedures to help establish credibility/ trustworthiness of the relevant data were used and clearly described/justified (e.g., triangulation, multiple coders)	Some evidence of use of verification procedure but not clearly described. Or it is not clear that the procedure helps to establish credibility/trustworthiness of the relevant data.	No verification procedures used/reported.
Are the claims/conclusion credible?	Sufficient original evidence supports the conclusions (e.g. quotes) A link to theory informs any claims of generalisability	The conclusions are only partly supported by the data. Or claims of generalisability are not supported	The conclusions are not supported by the data. Or conclusions are absent.

Key: Yes = 2; Partial = 1; No = 0

Appendix A4: Quality assessment scoring for included studies

Table A3. *Quality assessment tool scores for each paper within the review.*

	Becker, Swenson, Esposito-Smythers, Cataldo and Spirito (2014)	Breland-Noble, Wong, Childers, Hankerson and Sotomayor (2015)	Bullock, Nadeau and Renaud (2012)	Bussing, Koro-Ljungberg, Noguchi, Mason, Mayerson and Garvan (2012)	Chandra and Minkovitz (2007)
Question/objective sufficiently described	2	2	2	2	2
Are the research question/s suited to qualitative inquiry	2	2	2	2	2
Study design well described and appropriate	2	1	2	1	2
Context of study clear	2	1	2	2	2
Sampling strategy described, appropriate and justified	2	1	1	2	2
Data collection methods systematic, clearly described and appropriate for research question	1	1	2	2	2
Data analysis systematic, clearly described and appropriate for research question	1	1	1	1	1
Use of verification procedures to establish credibility	2	2	1	2	2
Are the claims/conclusion credible?	2	1	2	2	2
Total	16	12	15	16	17

	De Anstiss and Ziaian (2010)	Del Mauro and Jackson Williams (2013)	Fleming, Dixon and Merry (2012)	Fornos, Mika, Bayles, Serrano, Jimenez and Villarreal (2005)	Fortune, Sinclair and Hawton (2008a)
Question/objective sufficiently described	2	2	2	1	2
Are the research question/s suited to qualitative inquiry	2	2	2	2	2
Study design well described and appropriate	2	2	2	2	1
Context of study clear	2	2	2	2	2
Sampling strategy described, appropriate and justified	1	1	1	1	1
Data collection methods systematic, clearly described and appropriate for research question	1	2	1	1	2
Data analysis systematic, clearly described and appropriate for research question	1	1	1	1	1
Use of verification procedures to establish credibility	2	2	2	0	2
Are the claims/conclusion credible?	2	2	2	1	2
Total	15	16	15	11	15

	Fortune, Sinclair and Hawton (2008b)	Francis, Boyd, Aisbett, Newnham and Newnham (2006)	Goncalves and Moleiro (2012)	Huggins, Weist, McCall, Kloos, Miller and George (2016)	Kendal, Keeley and Callery (2014)
Question/objective sufficiently described	2	2	2	2	2
Are the research question/s suited to qualitative inquiry	2	2	2	2	2
Study design well described and appropriate	1	2	1	2	2
Context of study clear	2	2	2	2	2
Sampling strategy described, appropriate and justified	1	1	1	1	1
Data collection methods systematic, clearly described and appropriate for research question	1	2	1	1	1
Data analysis systematic, clearly described and appropriate for research question	1	1	1	1	2
Use of verification procedures to establish credibility	2	2	1	2	2
Are the claims/conclusion credible?	2	2	1	2	2
Total	14	16	12	15	16

	Klineberg, Kelly, Stansfeld and Bhui (2013)	Lindsey, Chambers, Pohle, Beall and Lucksted (2013)	Lindsey, Joe and Nebbitt (2010);	Lindsey, Korr, Broitman, Bone, Green and Leaf (2006)	McAndrew and Warne (2014)
Question/objective sufficiently described	2	2	2	2	2
Are the research question/s suited to qualitative inquiry	2	2	2	2	2
Study design well described and appropriate	2	2	2	2	2
Context of study clear	2	2	2	2	0
Sampling strategy described, appropriate and justified	2	1	1	1	0
Data collection methods systematic, clearly described and appropriate for research question	1	2	2	2	1
Data analysis systematic, clearly described and appropriate for research question	1	2	1	1	1
Use of verification procedures to establish credibility	2	2	2	2	2
Are the claims/conclusion credible?	2	2	2	2	1
Total	16	17	16	16	11

	Pailler, Cronholm, Barg, Wintersteen, Diamond and Fein (2009)	Prior (2012)	Timlin-Scalera, Ponterotto, Blumberg and Jackson (2003)	Wilson and Deane (2001)	Wisdom, Clarke and Green (2006)
Question/objective sufficiently described	2	2	2	2	2
Are the research question/s suited to qualitative inquiry	2	2	2	2	2
Study design well described and appropriate	2	2	2	2	2
Context of study clear	2	1	2	2	2
Sampling strategy described, appropriate and justified	2	1	1	1	1
Data collection methods systematic, clearly described and appropriate for research question	2	1	2	1	1
Data analysis systematic, clearly described and appropriate for research question	1	1	2	2	1
Use of verification procedures to establish credibility	2	2	2	2	2
Are the claims/conclusion credible?	2	2	1	2	2
Total	17	14	16	16	15

Appendix A5 - Thematic synthesis of qualitative studies

Twenty-three studies (25 papers; 2 papers reported different results from the same study – Fortune et al.(2008a, 2008b) and Lindsey et al. (2006, 2010) were included in the review.

A total of five over-arching barrier themes and five facilitator themes were developed through a thematic analysis of included studies.

Table A4. *Over-arching themes.*

Barrier themes	Number of studies
Concern about the consequences of seeking help	19
Psychological treatment is not wanted/not perceived to be needed	14
Lack of trust and confidence in mental health treatment and professionals	13
Limited understanding and awareness of mental health & services	9
Practical/logistical difficulties	6
Facilitator themes	
Trusting relationship with referrers and providers	10
Social support and encouragement from others	9
Motivation to seek help	8
Information and awareness about mental health and related services	7
Accessibility of mental health services	2

Over-arching themes with descriptive themes and line by line codes

The initial codes and related studies for each theme are shown below**.** The terminology used by the study authors was used where possible in the initial codes.

Barrier themes

Table A5. *Barrier theme: Concern about the consequences of seeking/accessing help.*

Descriptive theme	***Confidentiality concerns***	
Initial codes	Confidentiality concerns	Becker et al. (2014)
	Cannot trust professionals from same community	De Anstiss & Ziaian (2010)
	Concerns regarding confidentiality	Del Mauro & Jackson Williams (2013)
	Confidentiality	Fornos et al. (2005)
	Lack of anonymity	Francis et al. (2006)
	Teachers and school staff may share disclosure with others	Klineberg et al. (2013)
	Uncertainty about confidentiality	Kendal et al. (2014)
	Confidentiality/Trust - Fear that others would find out	Timlin-Scalera et al. (2003)
	Concerns about confidentiality	Wisdom et al. (2006)

Descriptive theme	***Self, other and family attitudes to mental illness and help-seeking***	
Social stigma & Shame	Stigma and shame of mental illness	De Anstiss & Ziaian (2010)
	Stigma – others will think I am weird/crazy	Del Mauro & Jackson Williams (2013)
	People make fun of you/call you names	Fornos et al. (2005)
	Being labelled as an 'attention-seeker' or a ‘psycho’	Fortune et al. (2008a)
	Feeling ashamed or embarrassed	Fortune et al. (2008a)
	Exclusionary social practices and fear of social stigma	Francis et al. (2006)
	Seeking help as a sign of weakness	Francis et al. (2006)
	Stigma/fear/shame	Goncalves & Moleiro (2012)
	Stereotyped as crazy or insane	Huggins et al. (2016)
	Worries about looking vulnerable to peers	Kendal et al. (2014)
	Peer group norms prevent help-seeking	Kendal et al. (2014)
	Weighing up the risks of being seen as inadequate/being judged	Kendal et al. (2014)
	Being teased or gossiped about by peers	Lindsey et al. (2013)
	Stigma – shame/embarrassment/ exclusion	Lindsey et al. (2006) Lindsey et al. (2010)
	Expressing emotions is a sign of weakness	Lindsey et al. (2006)
	Fear of being judged/Shame	McAndrew & Warne (2014)
	Stigmatisation	Prior (2012)
	Stigma	Timlin-Scalera et al. (2003)
	Not wanting an illness identity	Wisdom et al. (2006)
	Not wanting to be labelled as ‘mental’	Fleming et al. (2012)
Self-beliefs about mental health and help-seeking	Self-stigma	Francis et al. (2006)
	Going to a therapist makes you weird or crazy	Lindsey et al. (2013)
	Too much pride to go to formal MH services	Lindsey et al. (2006)
	Going to someone for help is a weakness	Timlin-Scalera et al. (2003)
	Seeking help is a weakness	Wisdom et al. (2006)
Family attitudes about mental health/help-seeking	Family stigma – negative views of therapy within the family	Becker et al. (2014)
	Parents would be upset or would deny the mental health issue	Chandra & Minkovitz (2007)

	Family avoidance of mental health issues	Chandra & Minkovitz (2007)
	Mental health concerns should be kept within the home	Chandra & Minkovitz (2007)
	Family privacy	De Anstiss & Ziaian (2010)
	Caregivers' reluctance to seek help	Pailler et al. (2009)
Concerns about being judged or dismissed by services	Concerns about being judged by service providers	Del Mauro & Jackson Williams (2013)
	Being labelled or dismissed by professional healthcare providers	Fornos et al. (2005)
	Fear of judgement from service providers as having insignificant problems, weird, stupid or crazy	Wisdom et al. (2006)
	Fear of being judged/shame about seeking help from GP	McAndrew & Warne (2014)
Descriptive theme: Making things worse		
Seeking help could make the situation worse	Makes things worse	Fornos et al. (2005)
	Seeking help would make the situation worse	Fortune et al. (2008a)
	Fear of potential consequences of seeking help at school	Klineberg et al. (2013)
	Fear that seeking help would impact college recommendations or grades	Timlin-Scalera et al. (2003)
Fear of being removed from parents	Legal consequences – child protection	Fornos et al. (2005)
	Fear of being removed from parents	Lindsey et al. (2013)
Not wanting to worry/upset/burden others	I will hurt or worry people who I care about	Fortune et al. (2008a)
	Not want to burden someone else	Timlin-Scalera et al. (2003)
	Family may be offended that they weren't able to help	Lindsey et al. (2013)

Table A6. *Barrier theme: Professional treatment is not wanted/not perceived to be needed.*

Descriptive theme	***A preference for self-reliance or informal support***	
Self-reliance	Ethic of self-reliance	Becker et al. (2014)
	Self-reliance	Del Mauro & Jackson Williams (2013)
	Individuals are responsible for their own recovery	Fornos et al. (2005)

	I can, or should be able to, cope on my own	Fortune et al. (2008a)
	Reliance on self-support	Goncalves & Moleiro (2012)
	Handle problems on own	Lindsey et al. (2006)
	Keep to oneself	Lindsey et al. (2013)
	Use themselves as resources for help	Timlin-Scalera et al. (2003)
	Do not want others to take care of them	Timlin-Scalera et al. (2003)
	Being autonomous	Wisdom et al. (2006)
	Individuals are solely responsible for own recovery	Fornos et al. (2005)
Informal support	Not venturing beyond informal networks	De Anstiss & Ziaian (2010)
	Preference for informal social support	Goncalves & Moleiro (2012)
	More inclined to use informal help resources	Timlin-Scalera et al. (2003)
Religion	Focus on prayer and church	Breland-Noble et al. (2015)
Descriptive theme	***Lack of interest in or perceived relevance of treatment support***	
Not interested in treatment/not needed/not relevant	Lack of interest or perceived relevance	Becker et al. (2014)
	Low priority placed on MH	De Anstiss & Ziaian (2010)
	Did not want help	Fortune et al. (2008a)
	Do not view SH as problematic	Klineberg et al. (2013)
	Lack insight into problems and need for services	Timlin-Scalera et al. (2003)
	Help-seeking is not always necessary	Wilson & Deane (2001)
	Normalising stress, minimising symptoms	Wisdom et al. (2006)
	Not wanting to face the problem/access help	Pailler et al. (2009)
Different aetiology/treatment beliefs	Social aetiology of MH	De Anstiss & Ziaian (2010)
	Cross-cultural differences in explanatory models	De Anstiss & Ziaian (2010)
	Different aetiology of depression (non-medical)	Wisdom et al. (2006)

Table A7. *Barrier theme: Lack of trust and confidence in mental health services/professionals.*

Descriptive theme	***MH professionals/services are not able to help***	
	Negative beliefs about capacity and willingness to help	De Anstiss & Ziaian (2010)
Descriptive theme	***Mental health professionals cannot be trusted***	
	Question the authenticity and genuineness of mental health professionals	Lindsey et al. (2010)
	Helping professionals are strangers	De Anstiss & Ziaian (2010)
	Not knowing the service provider personally	Fleming et al. (2012)
	MH staff are unavailable, inaccessible and unfamiliar	Timlin-Scalera et al. (2003)
Descriptive theme	***Treatment is not effective***	
	Negative attitudes and dislike of psychological treatment	Bussing et al. (2012)
	Limited effectiveness of treatment	Bussing et al. (2012)
	Counselling is not helpful	Chandra & Minkovitz (2007)
	Difficult to find a good therapist	Lindsey et al. (2013)
Descriptive theme	***Lack of cultural awareness***	
	Services have low cross-cultural awareness and competency	De Anstiss & Ziaian (2010)
	MH professionals lack cultural/community awareness	Lindsey et al. (2006)
Descriptive theme	***Negative experiences of services***	
	Negative experiences and feeling dissatisfied with services	Chandra & Minkovitz (2007)
Descriptive theme	***Lack of hope for improvement***	
	Nobody can help me	Fortune et al. (2008a)
	No one would understand and/or care	Fortune et al. (2008a)
Descriptive theme	***Not wanting hospital admission/medication***	
	Belief that treatment would involve going to hospital	Fornos et al. (2005)
	Services will prescribe medication	Wisdom et al. (2006)
Descriptive theme	***Difficulty communicating feelings and problems***	
Difficulty with interpersonal communication	Difficulty with inter-personal openness	Del Mauro & Jackson Williams (2013)

	Difficulty finding the words to communicate distress	Fortune et al. (2008a)
Overwhelming emotions impact help-seeking	Feeling scared, stupid or alone so not able to seek help	Fortune et al. (2008a)
	Difficulty accessing help due to difficulty verbalising intense feelings	Lindsey et al. (2013)
	Difficulty finding the courage to ask for help	McAndrew & Warne (2014)
	Too depressed or lethargic to access help	Wisdom et al. (2006)
	Difficulty of overcoming defensive mechanisms	Lindsey et al. (2010)

Table A8: *Barrier theme: Limited understanding/awareness of MH and/or available services.*

Descriptive theme	***Lack of knowledge about mental health***	
	Limited or inaccurate mental health information	Chandra & Minkovitz (2007)
	Lack of knowledge about mental health	De Anstiss & Ziaian (2010)
	Misconception about mental illness	De Anstiss & Ziaian (2010)
	Lack of knowledge about mental health	Huggins et al. (2016)
Descriptive theme	***Lack of awareness of mental health services***	
	Lack of awareness of and understanding of services	Timlin-Scalera et al. (2003)
	Didn’t know how to get help	Fortune et al. (2008a)
	No clear notion of where to go for help or what to expect	Klineberg et al. (2013)
	Not knowing where to go for help	McAndrew & Warne (2014)
	Uncertainty about what counselling might involve	Prior (2012)
	Lack of information about treatment	Wisdom et al. (2006)
	Lack of knowledge about MH services	De Anstiss & Ziaian (2010)
	Lack of knowledge about available mental health services	Huggins et al. (2016)

Table A9: *Barrier theme: Practical/logistical difficulties*

Descriptive theme	***Practical and logistical barriers***	
Lack of time	Time and effort concerns	Becker et al. (2014)

Difficulty being able to get to appointments	Logistical concerns	Becker et al. (2014)
	Transportation difficulties	Francis et al. (2006)
	Logistical barriers - transportation and insurance coverage	Pailler et al. (2009)
Financial concerns	Financial concerns	Becker et al. (2014)
	Cost	Fornos et al. (2005)
	Financial reasons	Goncalves & Moleiro (2012)
Lack of services	Perceived lack of specialist local services	Francis et al. (2006)
	External constraints - lack of services	Lindsey et al. (2013)
Language issues	Language issues	Goncalves & Moleiro (2012)

Facilitators themes

Table A10: *Facilitator theme: Trusting relationship.*

Trusting relationship facilitates help-seeking		
	Being able to trust the helping professional is more important than cultural background	De Anstiss & Ziaian (2010)
	Seek help from non-teaching staff (more trustworthy)	Kendal et al. (2014)
	Trusting relationship	Lindsey et al. (2006)
	Professional lets you know they're available to help	Wilson & Deane (2001)
	Trust	Wilson & Deane (2001)
	Strong, open relationship	Wilson & Deane (2001)
	Prefer to seek help from professionals *not* from same culture/same area	Klineberg et al. (2013)
Being understood	More likely to seek help from same-culture professional	De Anstiss & Ziaian (2010)
	Prefer to seek help from professionals of similar age/background	Klineberg et al. (2013)
	Provider from same race/background	Lindsey et al. (2006)
	Feeling connected with mental health professional - feeling listened to and understood	Wisdom et al. (2006)
	Expressions of empathy	Wisdom et al. (2006)
Emphasising choice and collaboration	Promotion of young person's choice	Prior (2012)
	Professionals listening to family and adolescent perspectives	Wisdom et al. (2006)
	Healthcare providers working with adolescents to find solutions	Wisdom et al. (2006)
	Not being judged	McAndrew & Warne (2014)
Problem normalisation	Normalising problems	Fortune et al. (2008b)
	Problem normalization	Wilson & Deane (2001)
	Normalising distress	Prior (2012)
Confidentiality		
	Confidentiality	McAndrew & Warne (2014)
	Online services allow anonymity	McAndrew & Warne (2014)
	Confidentiality and respect	Klineberg et al. (2013)

	Self-referral to counselling promises privacy	Kendal et al. (2014)
	External services assure confidentiality	Prior (2012)
	Confidentiality	Wisdom et al. (2006)
	Assured confidentiality	Timlin-Scalera et al. (2003)

Table A11: *Facilitator theme: Social support and encouragement from others.*

Social network support & encourage help-seeking		
	Parents force students to seek help	Fornos et al. (2005)
	Social network serve as facilitators to accessing mental health care	Goncalves & Moleiro (2012)
	Importance of support from friends and family to access professional help	Pailler et al. (2009)
	Accessing help through teachers	McAndrew & Warne (2014)
	MH outreach/referrals	Timlin-Scalera et al. (2003)
	Encouragement and motivation	Pailler et al. (2009)
	Teachers encourage use of counselling	Pailler et al. (2009)
	Family pressure to seek help	Lindsey et al. (2013)
	Help-seeking initiated by family and teachers	Wilson & Deane (2001)
	Someone suggesting help-seeking	Timlin-Scalera et al. (2003)
Conversations about mental health increases help-seeking		
	Family conversations about mental health	Chandra & Minkovitz (2007)
	Peer conversations about mental health	Chandra & Minkovitz (2007)
	A culture of openness in their homes	Timlin-Scalera et al. (2003)
Religious network facilitates help-seeking		
	Religious community members as a bridge/step to services	Bullock et al. (2012)

Table A12: *Facilitator theme: Motivation to seek help.*

Seriousness of the problem		
	Serious problem	**Del Mauro & Jackson Williams (2013)**
	Thoughts, feelings and behaviours are not 'normal'	**Wisdom et al. (2006)**
	Having a very serious problem	**Timlin-Scalera et al. (2003)**
Religion as treatment incentive		
	Religion as Treatment Incentive	**Breland-Noble et al. (2015)**
Positive attitude towards seeking help		
	Belief that therapy can help and that a youth needing help should get it	**Lindsey et al. (2013)**
	Potential benefits greater than the risks	**Kendal et al. (2014)**
	Seeking help reflects positively on the help-seeker	**Lindsey et al. (2013)**
Positive experiences of mental health services		
	Positive experiences of MH care – self and friends/family	**Chandra & Minkovitz (2007)**
	Positive experience of MH services	**Timlin-Scalera et al. (2003)**
	Successful prior help seeking	**Wilson & Deane (2001)**

Table A13: *Facilitator theme: Information and awareness about mental health and MHS.*

Providing information about mental health and services		
	Publicise services	**Huggins et al. (2016)**
	Raise awareness of MH and services	**McAndrew & Warne (2014)**
	Providing information about/contact with service when making referrals	**Pailler et al. (2009)**
	Demystifying/normalising counselling	**Prior (2012)**
	Raise awareness of available support	**Timlin-Scalera et al. (2003)**
	Education about help-seeking	**Wilson & Deane (2001)**
	Wanting to know more information about depression	**Wisdom et al. (2006)**
Developing knowledge about help-seeking from social network		
	School staff discuss and explain counselling process	**Prior (2012)**

	Knowledge about help-seeking from peer discussion	**Wilson & Deane (2001)**
	Knowledge of help-seeking from prior help-seeking	**Wilson & Deane (2001)**

Table A14: *Facilitator theme: Availability/accessibility of mental health services*.

Overcoming logistical barriers		
	Practical suggestions for overcoming logistical barriers	Pailler et al. (2009)
Availability of services		
	More counsellors available would facilitate help-seeking	McAndrew & Warne (2014)

Appendix B1: Interview topic guide

Knowledge / beliefs about anxiety in children

- Can you tell me what you know about anxiety problems in children?
  (Probe for understanding of anxiety disorders in children)
  - *Probe:* How may a child experiencing problems with anxiety behave? What difficulties may they have?
  - *Probe:* Have you ever known another child (or adult) who has had problems with anxiety?

Parental recognition

- The questionnaires and assessment asked you about any anxieties, fears or worries your child is experiencing. Can you tell me about your answers?
  - *Probe:* Do you think your child is experiencing problems with anxiety?
  - *Probe*: Can you tell me about when you first thought your child may be experiencing problems with anxiety?
  - *Probe:* Did you or someone else notice any change in your child?
  - *Probe:* Was their anxiety affecting their life at home / at school / friendships / other activities?
  - *Probe:* Was there any affect on your family? How about you?
  - *Probe:* Did you talk to another adult about it?

Knowledge / views about / experience of help seeking

- Do you think children should have any help with anxiety?
  - *Probe:* Where do you think this should come from? (eg family, friends, school, health professionals, church, alternative therapies, osteopath, reflexology, aromatherapy, or other sources?)

- Has your child had any help or support with their anxiety?
  (Probes for reasons for help seeking and any steps taken to seek help)
  - *Probe:* What made you decide to seek help?
  - *Probe:* What type of help/support?
  - *Probe:* Where did you go / who did you first speak to? (eg GP, teacher)
  - *Probe:* Did both you and your child agree about the need for support?
  - *Probe:* Did you and your child agree about the type of support?

- Have you ever tried to get any support to help with your child’s anxiety? What happened?
  (Probe for (failed) attempts to seek help / outcome of steps taken)
  - *Probe:* Have you faced any difficulties getting help for your child?
  - *Probe:* Is there anything that made it harder?

- Is there anything that made the process of getting help easier for your family?
  (Probe for factors that facilitated help seeking and accessing professional help)

If no attempt has been made to access professional/clinical help:

- How much do you know about the help or support that is available for children who are experiencing problems with anxiety?

  (Probe for knowledge/views about sources of professional/clinical help)
    - *Probe:* Where can you go to ask for help? / Who can you speak to about getting help?

- What do you think are some of the difficulties/challenges a family may face getting support for their child?
  (Probe for perceptions about accessing help and personal reasons for not seeking help / failing to access professional help)
    - *Probe:* Did anything make it difficult for you / stop you from trying to seek help?
    - *Probe:* Were you concerned getting help could make the problem worse? (eg labelling, stigma)
    - *Probe:* Did anything make it difficult for your child to get professional help?
    - *Probe:* What do you think may prevent a family from getting professional help?

- What do think may help a family get professional help/support?

Knowledge / experience of support services

If accessed services:

- Can you tell me about yours and your child's experience with getting help for your child's difficulties?
    - *Probe:* What did you think about the services your family received?
    - *Probe:* What was the outcome? Did it help your child/ you/your family?
    - *Probe:* Would you recommend to a friend that they sort help? Help of this kind?

If not accessed services:

- Have you had any experience with any kind of support services for children having problems with anxiety?
  (Probe for any personal experience / perceptions about CAMHS/GPs)

Suggested improvements

- What improvements could be made to make it easier for families get help or support if their child is having problems with anxiety?
- What type of support do you think should be available for children with anxiety disorders?
  (Probe for perceived 'ideal' service - the steps that would be involved in accessing help / where and who families would go to access help / nature of services and help offered)

Appendix B2: Ethical approval from University of Southampton

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Actions

To:

M

Evdoka-Burton G.

18 April 2017 12:20

Submission Number: 26383
Submission Name: Experiences of parenting a child with an anxiety disorder: a secondary analysis of qualitative data
This is email is to let you know your submission was approved by the Ethics Committee.

Comments
1.Thanks for making the changes so quickly. Good luck with your research!

Click here to view your submission
Coordinator: Georgina Evdoka-Burton

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ERGO : Ethics and Research Governance Online
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Appendix B3: Parent consent forms

University of Reading

School of Psychology and Clinical Language Sciences
University of Reading
Earley Gate
Whiteknights Road
Reading
RG6 6AL

Parent's Consent Form

Research Study: I-CAT (Improving access to Child Anxiety Treatment)

	Please tick box to show agreement.
1. I confirm that I have read and understand the information leaflet for the above study. I have had the opportunity to consider the information, ask questions and (if applicable) have had these answered satisfactorily.	
2. I understand that my and my child's participation is voluntary and that we are free to withdraw at any time, without giving a reason.	
3. I agree to my child's teacher being contacted to provide information.	
4. I agree to researchers contacting me if responses given on questionnaires completed by me, my child or my child's teacher suggest my child may be experiencing problems with fears, worries or anxiety. I understand these questionnaires are not always accurate so we will be offered a more detailed assessment of my child's anxiety.	
5. I understand that the project has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion of conduct.	
6. I agree to take part in this study.	

Your Child's Full Name _________________________

School name_____________________________ Year group____________________

Your Full Name ______________________________Relationship to Child:_________________________

Address:__________________________ ____

Email:________________________ Telephone:____

Signed _____________________________________Date ______________________________________

Appendix B4: Reflexive log extract

Initial reading of interview transcripts

- Surprising that a number of parents struggled to define anxiety, and discussed being unsure about this – but all have a child with an anxiety disorder. Perhaps this indicates that parents do not feel they hold this knowledge, or perhaps a belief that their child is not necessarily representative. Does the term/label ‘anxiety disorder’ resonate with these parents?
- Also, a number of parents discuss co-morbidities and do not separate anxiety symptoms from other characteristics of their child e.g. dyslexia, sensory, attentional issues/autistic features – perhaps indicating that the labels and diagnostic systems used by MHS hold little value or meaning with parents. Interesting, if children do have additional needs then this may partially explain the anxiety – I wonder what percentage of children with a diagnosed anxiety disorder have co-morbidities?
- *I am noticing that my own interest in discourses related to the power of the medical profession, including psychology is influencing my reading of the data. While this may add an interesting interpretation, important to notice what other interpretations may be made of this data. In discussion with my thesis supervisor, he suggested that parents may be hoping for clear distinctions between diagnostic labels, whereas clinicians may not work in this way. This was a useful point, and enabled me to stand back and reflect on my own assumptions.*
- Parents also talk about how changeable their child’s behaviour can be – and link this to different environments, interesting as this may seem to locate difficulties as being environmental rather than internalised and perhaps this speaks about parents’ understanding of their child’s difficulties and associated treatment. *It is interesting that I have noticed this in the material, given my own interests as a systemic therapist and an assumption that ‘problems’ are situated in relationships and the influence of socio-cultural discourses. How might this be a useful interpretation, in terms of clinical implications?*
- School and academic pressure seems to be linked to anxiety and the impact of school life at home – school pressure perpetuating anxiety, but schools not being responsible for help and support. *This point resonates with an experience on my own personal life, where friends have felt pressure but lack of support from the school when their child has a mental health difficulty. While this may be a useful insight, this also might reflect only one dimension of the data – so it will be useful to look for cases that disconfirm this interpretation, or add different nuances of meaning.*
- *I am particularly drawn to aspects of the data which speak about the discrepancy between medical/psychological/professional understandings and meanings, and parents’ lay understandings. This seems to be focusing my attention on data related to the difficulties of professional help-seeking. Discussed this in supervision, my analysis needs to be distinct from a previous analysis which focuses on parents experiences of seeking professional help. I initially felt disappointed by this, seeing this as a key aspect of the data. However, after discussion with my supervisor and on reading the data through a different lens, I was able to see how much material related to parents’ experiences of their child’s difficulties that is not directly related to seeking help from professionals. Important to keep this awareness about my own assumptions and research interests.*

Appendix B5: Thematic analysis

Table B1. *Breakdown of the individual themes within the thematic analysis.*

Over-arching theme	Themes	Sub-themes
Helplessness	Beyond my control	Anxiety quick to escalate/difficult to manage
		Born this way
		Nothing (else) I can do Peers/school/real life/know too much
		Child cannot manage emotions
		Normal behaviour?
	Uncertainty & doubt	Unaware/uncertain about what's wrong
		Uncertainty about how to manage
		Something else is going on?
Emotional & demanding	Emotional distress	Worry & concern
		Anger & frustration
		Guilt & self-blame
		Sadness & grief
	Isolated & alone	Others don't see the problem
		Not talking to others
		Stigma & self-blame
	Exhausted & draining	Dealing with challenging behaviour
		Extra pressure on family life
		End of my tether
Hard work & effort	Making sense of anxiety	Finding out information/learning about anxiety
		Understanding my child's anxiety
		Learning from my own experience
		Speaking to others with experience
		Different issues to manage
		Using different strategies
		Adapting to cope with anxiety
		Accommodating anxiety
		Crisis management
	Finding ways to manage	

Over-arching theme	Themes	Sub-themes
		Managing it ourselves
		Trying everything
	Trying my best	Protecting my child
		Peace keeper/stuck in the middle
		My child is going to come out of it
Hopefulness & progression	Anticipating/experiencing progression	Realising anxiety can be helped
		Seeing improvements
		You learn to deal with it
		Talking to others with experience
	Connecting with others	Getting ideas/advice/support
		Knowing I’m not alone
		Brought me closer to other people
		Supporting other parents

Appendix B6: Measures used in primary study

Spence Children's Anxiety Scale – Child (SCAS-C)

The SCAS-C is a questionnaire measuring child anxiety symptoms, consisting of 44 items: 38 items addressing symptoms of DSM anxiety disorders, and 6 filler items. Items are rated on a four-point scale (never=0; sometimes=1; often=2; always=3). The sum of responses to the 38 anxiety items provide a total score. The SCAS-C is a reliable and valid measure of child anxiety symptoms (Arendt, Hougaard & Thastum, 2014; Spence, Barrett & Turner, 2003; Whiteside & Brown, 2008) and excellent internal consistency was found within the current sample (*a* =.95) (Reardon et al., 2017b).

Spence Children's Anxiety Scale – Parent (SCAS-P)

The SCAS-P is a parent-report version of the SCAS-C, consisting of 38 items addressing symptoms of DSM anxiety disorders that correspond to the SCAS-C. Items are rated on the same scale; total scores reflect the sum of responses to all items. The SCAS-P has been found to have strong psychometric properties (Arendt et al., 2014; Nauta et al., 2004; Whiteside & Brown, 2008), with excellent internal consistency in the current sample (*a* =.91) (Reardon et al., 2017b).

Adapted Spence Children's Anxiety Scale – Teacher (SCAS-T)

The original research team (Reardon et al., 2017b) developed a teacher-report version of the SCAS-C/P, comprising of 30 items with the same four-point scale as the SCAS-C/P and the total score reflecting the sum of responses to all 30 items. Eight items that appear on the original measures were removed as they were considered inappropriate for teachers (e.g. 'I would feel afraid of being at home on my own') and the wording of items was amended to reflect the reporter (e.g. 'I worry about things' / 'My child worries about things' was changed to 'Worries about things').

Anxiety Disorders Interview Schedule-IV-Parent and Child Interview (ADIS-C/P)

The ADIS-C/P is a structured parent and child interview schedule consistent with DSM-IV anxiety diagnoses and common comorbid diagnoses and has strong psychometric properties (Silverman, Saavedra & Pina, 2001). The original research team made minor amendments to the interview schedules to in line with DSM-5 diagnostic criteria. The child and parent interviews were administered independently, with diagnoses and Clinical Severity Ratings (CSRs) assigned independently for each interview. As per the guidelines, a child met diagnostic criteria where the required symptoms were reported and a CSR from 4 to 8 was assigned. In cases where there were discrepancies between the child and parent report, the higher CSR was assigned as the overall CSR. With the exception of two interviews, all assessments were administered by one assessor, and for the first 20 assessments, interviews were discussed with an experienced clinician and a consensus reached. Assessor reliability was checked at this stage (with a minimum kappa/ICC of 0.85 required), and subsequently one in six interviews were discussed and consensus reached. Overall inter-rater reliability within the assessment team was excellent (child report diagnoses, kappa = .95; CSR ICC = .97; parent report diagnoses, kappa = .98, CSR ICC = .96) (Reardon et al., 2017b).

Appendix B7: Participant characteristics

Table B2. *Characteristics of participants.*

Participant characteristic	
Child	
n	16
medium age (range), years	8.9 (7.7-11.7)
female, *n* (%)	11 (68.8)
Parent[a]	
n	18
medium age (range), years	43.5 (25-54)
mother, *n* (%)	16 (88.9)
SES of the family	
Free school meals	
n (% of families)	3 (18.8)
Higher professional	
n (% of families)	9 (56.3)
ADIS Primary anxiety diagnosis *n* of children (%)	
Separation Anxiety Disorder	2 (12.5)
Social Anxiety Disorder	1 (6.3)
Generalised Anxiety Disorder	9 (56.3)
Specific Phobia	4 (25.0)
Primary anxiety diagnosis CSR *n* of children (%)	
CSR 4	10 (62.5)
CSR 5	4 (25.0)
CSR 6	6 (12.5)
Presence of anxiety and other disorders (based on ADIS) *n* of children (%)	
Separation Anxiety Disorder	3 (18.8)
Social Anxiety Disorder	5 (31.3)
Generalised Anxiety Disorder	10 (62.5)
Specific Phobia	7 (43.4)
Major Depressive Disorder	1 (6.3)
ADHD	2 (12.5)
ODD	1 (6.3)
Parent reported contact with GP and/or school staff for help or advice related to child's anxiety difficulties	9 (56.3)
Parent reported child had received referral to CAMHS (for anxiety or other difficulties)	6 (37.5)

[a] Two interviews were conducted with child's two parents

SES, socioeconomic status; ADIS, Anxiety Disorders Interview Schedule; CSR, Clinical Severity Rating; CAMHS, Child and Adolescent Mental Health Services.

List of References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Publications.

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: does it matter?. *Journal of health and social behavior*, 1-10.

Angold, A., Erkanli, A., Farmer, E. M. Z., Fairbank, J. A., Burns, B. J., Keeler, G., & Costello, E. J. (2002). Psychiatric disorder, impairment, and service use in rural African American and white youth. *Archives of General Psychiatry, 59*(10), 893-901. doi:10.1001/archpsyc.59.10.893

Angold, A., Messer, S. C., Stangl, D., Farmer, E. M., Costello, E. J., & Burns, B. J. (1998). Perceived parental burden and service use for child and adolescent psychiatric disorders. *American journal of public health, 88*(1), 75-80.

Arendt, K., Hougaard, E., & Thastum, M. (2014). Psychometric properties of the child and parent versions of Spence Children's Anxiety Scale in a Danish community and clinical sample. *Journal of anxiety disorders*, *28*(8), 947-956.

Ajzen, I. (2005). *Attitudes, personality, and behavior*. McGraw-Hill Education (UK).

Bandura, A. (1986). Social foundations of thought and action. *New York: Prentice–Hall*.

Barker, G. (2007). *Adolescents, social support and help-seeking behaviour: an international literature review and programme consultation with recommendations for action*. Geneva: World Health Organization.

Barnett-Page, E., & Thomas, J. (2009). *Methods for the synthesis of qualitative research: a critical review*. London: ESRC National Centre for Research Methods, Social Science Research Unit, Institute of Education, University of London.

Bazeley, P., & Jackson, K. (Eds.). (2013). *Qualitative data analysis with NVivo*. Sage Publications Limited.

Becker, S. J., Swenson, R., Esposito-Smythers, C., Cataldo, A., & Spirito, A. (2014). Barriers to Seeking Mental Health Services among Adolescents in Military Families. *Prof Psychol Res Pr, 45*(6), 504-513. doi:10.1037/a0036120.

Biddle, L., Donovan, J., Sharp, D., & Gunnell, D. (2007). Explaining non-help-seeking amongst young adults with mental distress: a dynamic interpretive model of illness behaviour. Sociology of health & illness, 29(7): 983–1002.

Bittner A, Egger HL, Erkanli A, Costello EJ, Foley DL, Angold A. (2007). What do childhood anxiety disorders predict? Journal of Child Psychology and Psychiatry, 48(12), 1174-1183.

Blum, L. M. (2007). Mother-blame in the Prozac nation: Raising kids with invisible disabilities. *Gender & Society*, *21*(2), 202-226.

Bolton, D. (2008). *What is mental disorder? An essay in philosophy, science and values.* Oxford University Press.

Bone, C., O'reilly, M., Karim, K., & Vostanis, P. (2015). 'They're not witches.…'Young children and their parents' perceptions and experiences of Child and Adolescent Mental Health Services. *Child: care, health and development*, *41*(3), 450-458.

Boonstra, N., Klaassen, R., Sytema, S., Marshall, M., De Haan, L., Wunderink, L., & Wiersma, D. (2012). Duration of untreated psychosis and negative symptoms — A systematic review and meta-analysis of individual patient data. *Schizophrenia Research, 142*(1–3), 12-19. doi:http://doi.org/10.1016/j.schres.2012.08.017

Boulter, E., & Rickwood, D. (2013). Parents' experience of seeking help for children with mental health problems. *Advances in Mental Health*, *11*(2), 131-142.

Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. sage.

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

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.

Braun, V., & Clarke, V. (2014). What can "thematic analysis" offer health and wellbeing researchers?. *International journal of qualitative studies on health and well-being, 9*.

Breland-Noble, A. M., Wong, M. J., Childers, T., Hankerson, S., & Sotomayor, J. (2015). Spirituality and religious coping in African American youth with depressive illness. *Ment Health Relig Cult, 18*(5), 330-341. doi:10.1080/13674676.2015.1056120

British Psychological Society. (2015). What good looks like in psychological services for children, young people and their families. *The Child & Family Clinical Psychology Review, 3.*

Bullock, M., Nadeau, L., & Renaud, J. (2012). Spirituality and Religion in Youth Suicide Attempters' Trajectories of Mental Health Service Utilization: The Year before a Suicide Attempt. *J Can Acad Child Adolesc Psychiatry, 21*(3), 186-193.

Burnard, P., Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Analysing and presenting qualitative data. *British dental journal*, *204*(8), 429-432.

Bussing, R., Koro-Ljungberg, M., Noguchi, K., Mason, D., Mayerson, G., & Garvan, C. W. (2012). Willingness to use ADHD treatments: A mixed methods study of perceptions by adolescents, parents, health professionals and teachers. *Social Science & Medicine, 74*(1), 92-100. doi:10.1016/j.socscimed.2011.10.009

Centre for Reviews and Dissemination (2009). Systematic Reviews: CRD's guidance for undertaking reviews in healthcare. University of York. Retrieved from: www.york.ac.uk/crd/guidance/

Chandra, A., & Minkovitz, C. S. (2007). Factors that Influence Mental Health Stigma Among 8th Grade Adolescents. *Journal of Youth and Adolescence, 36*(6), 763-774. doi:10.1007/s10964-006-9091-0

Chavira, D. A., Stein, M. B., Bailey, K., & Stein, M. T. (2004). Child anxiety in primary care: Prevalent but untreated. *Depression and Anxiety, 20*(4), 155-164. doi:10.1002/da.20039

Children’s Society (2008). The Good Childhood Inquiry: Health research evidence. London: Children’s Society.

Choate, P. W. (2011). Adolescent addiction: What parents need?. *Procedia-Social and Behavioral Sciences*, *30*, 1359-1364.

Ciarrochi, J., Wilson, C., Deane, F. & Rickwood, D. (2003). Do difficulties with emotions inhibit help-seeking in adolescence? The role of age and emotional competence in predicting help-seeking intentions. Counselling Psychology Quarterly. 16(2): 103-120.

Clarke, V., Braun, V., & Hayfield, N. (2015). Thematic Analysis. Inmith JA. editor. Qualitative psychology: a practical guide to research methods.

Cohen, P., & Hesselbart, C. S. (1993). Demographic-Factors in the Use of Childrens Mental-Health-Services. *American Journal of Public Health, 83*(1), 49-52.

Copeland, W.E., Miller-Johnson, S., Keeler, G., Angold, A. & Costello, E.J. (2007). Childhood psychiatric disorders and young adult crime: a prospective, population-based study. *American Journal of Psychiatry* 164:1668–75.

Costello, E. J., Mustillo, S., Erkanli, A., Keeler, G., & Angold, A. (2003). Prevalence and development of psychiatric disorders in childhood and adolescence. *Archives of general psychiatry*, *60*(8), 837-844.

Cottee-Lane, D., Pistrang, N., & Bryant-Waugh, R. (2004). Childhood onset anorexia nervosa: The experience of parents. *European eating disorders review*, *12*(3), 169-177.

Creswell, C., Waite, P., & Cooper, P. J. (2014). Assessment and management of anxiety disorders in children and adolescents. *Archives of disease in childhood,* archdischild-2013.

Creswell, C., Cooper, P. J., & Murray, L. (2015). Parents with anxiety disorders. *Parental Psychiatric Disorder: Distressed Parents and their Families*, 127.

De Anstiss, H., & Ziaian, T. (2010). Mental health help-seeking and refugee adolescents: Qualitative findings from a mixed-methods investigation. *Australian Psychologist, 45*(1), 29-37. doi:10.1080/00050060903262387.

de Girolamo, G., Dagani, J., Purcell, R., Cocchi, A., McGorry, P.D. (2012). Age of onset of mental disorders and use of mental health services: needs, opportunities and obstacles. Epidemiology and Psychiatric Sciences 21, 47-57.

Del Mauro, J. M., & Jackson Williams, D. (2013). Children and Adolescents’ Attitudes Toward Seeking Help From Professional Mental Health Providers. *International Journal for the Advancement of Counselling, 35*(2), 120-138. doi:10.1007/s10447-012-9172-6

Department of Health (2015). Future in mind: Promoting, protecting and improving our children and young people’s mental health and wellbeing. Retrieved from: www.gov.uk/government/uploads/system/uploads/attachment_data/file/414024/Childrens_Mental_Health.pdf

Department of Health (2004). National Service Framework for Children, Young People and Maternity Services. London: Department of Health.

Department for Education (2015). Mental health and behaviour in schools: Departmental advice for school staff. Accessed 18 July 2015, from: www.gov.uk/government/uploads/system/uploads/attachment_data/file/416786/Mental_Health_and_ Behaviour_-_Information_and_Tools_for_Schools_ 240515.pdf

Dixon-Woods, M., Shaw, R. L., Agarwal, S., & Smith, J. A. (2004). The problem of appraising qualitative research. *Qual Saf Health Care*, *13*. doi:10.1136/qshc.2003.008714

Duchesne, S., Vitaro, F., Larose, S., & Tremblay, R. E. (2008). Trajectories of anxiety during elementary-school years and the prediction of high school noncompletion. *Journal of youth and adolescence*, *37*(9), 1134-1146.

Eaton, K., Ohan, J. L., Stritzke, W. G., & Corrigan, P. W. (2016). Failing to meet the good parent ideal: self-stigma in parents of children with mental health disorders. *Journal of Child and Family Studies*, *25*(10), 3109-3123.

Eaton, K., Ohan, J. L., Stritzke, W. G., Courtauld, H. M., & Corrigan, P. W. (2017). Mothers' Decisions to Disclose or Conceal Their Child's Mental Health Disorder. *Qualitative Health Research*, 1049732317697096.

Farmer, E. M., Burns, B. J., Angold, A., & Costello, E. J. (1997). Impact of children's mental health problems on families: Relationships with service use. *Journal of Emotional and Behavioral Disorders*, *5*(4), 230-238.Fineberg, N. A., Haddad, P. M., Carpenter, L., Gannon, B., Sharpe, R., Young, A. H., ... & Sahakian, B. J. (2013). The size, burden and cost of disorders of the brain in the UK. *Journal of Psychopharmacology*, *27*(9), 761-770.

Firmin, M. W., & Phillips, A. (2009). A qualitative study of families and children possessing diagnoses of ADHD. *Journal of Family Issues, 30*(9), 1155-1174.

Fleming, T. M., Dixon, R. S., & Merry, S. N. (2012). 'It's mean!' The views of young people alienated from mainstream education on depression, help seeking and computerised therapy. *Advances in Mental Health, 10*(2), 195-203. doi:10.5172/jamh.2011.10.2.195

Flink, E., Beirens, T., Butte, D. & Raat, H. (2014). Help-seeking behaviour for internalizing problems: perceptions of adolescent girls from different ethnic backgrounds. Ethnicity & Health, Vol. 19, No. 2, 160_177, http://dx.doi.org/10.1080/13557858.2013.801402

Ford, T., Hamilton, H., Meltzer, H., & Goodman, R. (2008). Predictors of Service Use for Mental Health Problems Among British Schoolchildren. *Child and Adolescent Mental Health, 13*(1), 32-40. doi:10.1111/j.1475-3588.2007.00449.x

Fornos, L. B., Mika, V. S., Bayles, B., Serrano, A. C., Jimenez, R. L., & Villarreal, R. (2005). A qualitative study of Mexican American adolescents and depression. *Journal of School Health*, *75*(5), 162-170. doi:DOI 10.1111/j.1746-1561.2005.00017.x

Fortune, S., Sinclair, J., & Hawton, K. (2008a). Adolescents' views on preventing self-harm. *Social Psychiatry and Psychiatric Epidemiology*, *43*(2), 96-104. doi:10.1007/s00127-007-0273-1

Fortune, S., Sinclair, J., & Hawton, K. (2008b). Help-seeking before and after episodes of self-harm: a descriptive study in school pupils in England. *BMC Public Health, 8*. doi:Artn 369

Francis, K., Boyd, C., Aisbett, D., Newnham, K., & Newnham, K. (2006). Rural adolescents' attitudes to seeking help for mental health problems. *Youth Studies Australia, 25*(4), 42.

Francis, A. (2012). Stigma in an era of medicalisation and anxious parenting: how proximity and culpability shape middle-class parents' experiences of disgrace. *Sociology of health & illness*, *34*(6), 927-942.

Futh, A., Simonds, L. M., & Micali, N. (2012). Obsessive-compulsive disorder in children and adolescents: parental understanding, accommodation, coping and distress. *Journal of Anxiety Disorders*, *26*(5), 624-632.

Geertz, C. (1973). *The interpretation of cultures* (Vol. 5019). Basic books.

Gergen, K. J. (1994). Exploring the postmodern: Perils or potentials?. *American psychologist*, *49*(5), 412.

Ginsburg, G. S., Becker, E. M., Keeton, C. P., Sakolsky, D., Piacentini, J., Albano, A. M., & Peris, T. (2014). Naturalistic follow-up of youths treated for pediatric anxiety disorders. *JAMA psychiatry*, *71*(3), 310-318.

Goncalves, M., & Moleiro, C. (2012). The Family-School-Primary Care Triangle and the Access to Mental Health Care Among Migrant and Ethnic Minorities. *Journal of Immigrant and Minority Health, 14*(4), 682-690. doi:10.1007/s10903-011-9527-9

Green, H., McGinnity, Á., Meltzer, H., Ford, T., & Goodman, R. (2005). Mental health of children and young people in Great Britain, 2004.

Gulliver, A., Griffiths, K. M., Christensen, H., & Brewer, J. L. (2012). A systematic review of help-seeking interventions for depression, anxiety and general psychological distress. *BMC Psychiatry, 12*(1), 81. doi:10.1186/1471-244x-12-81

Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry, 10*(1), 1.

Heaton, J. (2004). *Reworking qualitative data*. Sage.

Heaton, J. (2008). Secondary analysis of qualitative data: An overview. *Historical Social Research/Historische Sozialforschung*, 33-45.

Henshaw, E. J., & Freedman-Doan, C. R. (2009). Conceptualizing mental health care utilization using the health belief model. *Clinical Psychology: Science and Practice*, *16*(4), 420-439.

Hill, C., Waite, P., & Creswell, C. (2016). Anxiety disorders in children and adolescents. *Paediatrics and Child Health, 26*(12), 548-553.

Hinds, P. S., Vogel, R. J., & Clarke-Steffen, L. (1997). The possibilities and pitfalls of doing a secondary analysis of a qualitative data set. *Qualitative health research*, *7*(3), 408-424.

Hirshfeld-Becker, D. R., Biederman, J., Henin, A., Faraone, S. V., Davis, S., Harrington, K., & Rosenbaum, J. F. (2007). Behavioral inhibition in preschool children at risk is a specific predictor of middle childhood social anxiety: a five-year follow-up. *Journal of Developmental & Behavioral Pediatrics*, *28*(3), 225-233.

Hoskins, M. L., & Lam, E. (2003). The impact of daughters' eating disorders on mothers' sense of self: Contextualising mothering experience. *Canadian Journal of Counselling, 35,* 157-175.

Howitt, D. (2010). *Introduction to qualitative methods in psychology*. Harlow: Prentice hall.

Huggins, A., Weist, M. D., McCall, M., Kloos, B., Miller, E., & George, M. W. (2016). Qualitative analysis of key informant interviews about adolescent stigma surrounding use of school mental health services. *International Journal of Mental Health Promotion, 18*(1), 21-32. doi:10.1080/14623730.2015.1079424

Huxley, C. J., Clarke, V., & Halliwell, E. (2011). “It’s a comparison thing, isn’t it?” Lesbian and bisexual women’s accounts of how partner relationships shape their feelings about their body and appearance. *Psychology of Women Quarterly, 35*(3), 415-427.

ICD-10 Classifications of Mental and Behavioural Disorder: Clinical Descriptions and Diagnostic Guidelines. Geneva. World Health Organisation. 1992.

Jackson, D., & Mannix, J. (2004). Giving voice to the burden of blame: A feminist study of mothers’ experiences of mother blaming. *International journal of nursing practice, 10*(4), 150-158.

James, A.C., James, G., Cowdrey, F.A., Soler, A. & Choke, A. (2015). Cognitive behavioural therapy for anxiety disorders in children and adolescents. Cochrane Database of Systematic Reviews. Issue 2. Art.No.: CD004690. DOI: 10.1002/14651858.CD004690.pub4.

Kataoka, S. H., Zhang, L., & Wells, K. B. (2002). Unmet need for mental health care among US children: Variation by ethnicity and insurance status. *American Journal of Psychiatry, 159*(9), 1548-1555. doi:DOI 10.1176/appi.ajp.159.9.1548

Kendal, S., Keeley, P., & Callery, P. (2014). Student help seeking from pastoral care in UK high schools: a qualitative study. *Child and Adolescent Mental Health, 19*(3), 178-184. doi:10.1111/camh.12029

Kessler, R., Angermeyer, M., Anthony, J., DE Graaf, R., Demyttenaere, K., Gasquet, I., de Girolamo, G., Gluzman, S., Gureje, O., Haro, J., Kawakami, N., Karam, A., Levinson, D., Medina Mora, M., Oakley Browne, M., Posada-Villa, J., Stein D., Adley Tsang, C., Aguilar-Gaxiola, S., Alonso, J., Lee, S., Heeringa, S., Pennell, B., Berglund, P., Gruber, M., Petukhova, M., Chatterji, S. & Ustün, T. (2007). Lifetime prevalence and age-of-onset distributions of mental disorders in the World Health Organization's World Mental Health Survey Initiative. *World Psychiatry*. Oct;6 (3):168-76.

Kessler, R., Berglund, P., Demler, O., Jin, R., Merikangas, K.R. & Walters, E. (2005a). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. Archives of General Psychiatry. 62(6):593-602.

Kessler, R. C., Chiu, W. T., Demler, O., & Walters, E. E. (2005b). Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of general psychiatry*, *62*(6), 617-627.

King, E. (1996). The use of the self in qualitative research. JTE (Ed) *Handbook of Qualitative Research Methods for Psychology and the Social Sciences*, Leicester, BPS Books.

Klineberg, E., Kelly, M. J., Stansfeld, S. A., & Bhui, K. S. (2013). How do adolescents talk about self-harm: a qualitative study of disclosure in an ethnically diverse urban population in England. *BMC Public Health*, *13*. doi:Artn 572 10.1186/1471-2458-13-572

Kmet, L., Lee, R., & Cook, L. (2004). Standard quality assessment criteria for evaluating primary research papers from a variety of fields. Alberta Heritage Foundation for Medical Research.

Knapp, M., King, D., Healey, A., & Thomas, C. (2011). Economic outcomes in adulthood and their associations with antisocial conduct, attention deficit and anxiety problems in childhood. *Journal of Mental Health Policy and Economics*, *14*(3), 137-147.

Knock, J., Kline, E., Schiffman, J., Maynard, A., & Reeves, G. (2011). Burdens and difficulties experienced by caregivers of children and adolescents with schizophrenia-spectrum disorders: A qualitative study. *Early Intervention in Psychiatry*, *5*(4), 349-354.

Kohn, R., Saxena, S., Levav, I. & Saraceno, B. (2004). The treatment gap in mental health care. Bulletin of the World Health Organisation.82:858–66.

Lehrer, J.A., Shrier, L.A., Gortmaker, S. & Buka, S. (2006). Depressive symptoms as a longitudinal predictor of sexual risk behaviors among U.S. middle and high school students. *Pediatrics*; 118:189-200.

Lewinsohn, P. M., Zinbarg, R., Seeley, J. R., Lewinsohn, M., & Sack, W. H. (1997). Lifetime comorbidity among anxiety disorders and between anxiety disorders and other mental disorders in adolescents. *Journal of anxiety disorders*, *11*(4), 377-394.

Lindsey, M. A., Chambers, K., Pohle, C., Beall, P., & Lucksted, A. (2013). Understanding the Behavioral Determinants of Mental Health Service Use by Urban, Under-Resourced Black Youth: Adolescent and Caregiver Perspectives. *Journal of Child and Family Studies, 22*(1), 107-121. doi:10.1007/s10826-012-9668-z

Lindsey, M. A., Joe, S., & Nebbitt, V. (2010). Family Matters: The Role of Mental Health Stigma and Social Support on Depressive Symptoms and Subsequent Help Seeking Among African American Boys. *Journal of Black Psychology, 36*(4), 458-482. doi:10.1177/0095798409355796

Lindsey, M. A., Korr, W. S., Broitman, M., Bone, L., Green, A., & Leaf, P. J. (2006). Help-seeking behaviors and depression among African American adolescent boys. *Social Work*, *51*(1), 49-58.

Manassis, K., Russell, K. & Newton, A.S. (2010). The Cochrane Library and the treatment of childhood and adolescent anxiety disorders: an overview of reviews. Evidence-based Child Health 5:541–54.

Marsh, D. T., & Johnson, D. L. (1997). The family experience of mental illness: implications for intervention. *Professional Psychology: research and practice*, *28*(3), 229.

Mays, N., & Pope, C. (2000). Qualitative research in health care: assessing quality in qualitative research. *Br Med J, 320*. doi:10.1136/bmj.320.7226.50

Maskill, V., Crowe, M., Luty, S., & Joyce, P. (2010). Two sides of the same coin: caring for a person with bipolar disorder. *Journal of psychiatric and mental health nursing*, *17*(6), 535-542.

McAndrew, S., & Warne, T. (2014). Hearing the voices of young people who self-harm: Implications for service providers. *International Journal of Mental Health Nursing, 23*(6), 570-579. doi:10.1111/inm.1209

McCann, T. V., Lubman, D. I., & Clark, E. (2011). Responding to stigma: first-time caregivers of young people with first-episode psychosis. *Psychiatric Services*, *62*(5), 548-550.

McDonald, G., O'Brien, L., & Jackson, D. (2007). Guilt and shame: experiences of parents of self-harming adolescents. *Journal of Child Health Care*, *11*(4), 298-310.

Merikangas, K. R., He, J. P., Burstein, M., Swendsen, J., Avenevoli, S., Case, B., & Olfson, M. (2011). Service utilization for lifetime mental disorders in US adolescents: results of the National Comorbidity Survey–Adolescent Supplement (NCS-A). *Journal of the American Academy of Child & Adolescent Psychiatry*, *50*(1), 32-45.

Merikangas, K.R., He, J.P., Burstein, M., Swanson, S.A., Avenevoli, S., Cui, L., Benjet, C., Georgiades, K. & Swendsen, J. (2010). Lifetime prevalence of mental disorders in U.S. adolescents: results from the National Comorbidity Survey Replication. Journal of the American Academy of Child & Adolescent Psychiatry, 49:980–989.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement. *PLOS Med, 6.* doi:10.1371/journal.pmed.1000097

Morrow, V., Boddy, J., & Lamb, R. (2014). The ethics of secondary data analysis: Learning from the experience of sharing qualitative data from young people and their families in an international study of childhood poverty.

Moses, T. (2010). Exploring Parents' Self-Blame in Relation to Adolescents' Mental Disorders. *Family Relations*, *59*(2), 103-120.

Murphy, M., & Fonagy, P. (2012). Mental health problems in children and young people. *Annual report of the chief medical officer*.

Nauta, M. H., Scholing, A., Rapee, R. M., Abbott, M., Spence, S. H., & Waters, A. (2004). A parent-report measure of children's anxiety: psychometric properties and comparison with child-report in a clinic and normal sample. *Behaviour research and therapy*, *42*(7), 813-839.

Nock, M. K., & Ferriter, C. (2005). Parent management of attendance and adherence in child and adolescent therapy: A conceptual and empirical review. *Clinical child and family psychology review*, *8*(2), 149-166.

Noyes, J. & Lewin, S. Chapter 6: Supplemental Guidance on Selecting a Method of Qualitative Evidence Synthesis, and Integrating Qualitative Evidence with Cochrane Intervention Reviews. In: Noyes J, Booth A, Hannes K, Harden A, Harris J, Lewin S, Lockwood C (editors), *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions.* Version 1 (updated August 2011). Cochrane Collaboration Qualitative Methods Group, 2011. Available from URL http://cqrmg.cochrane.org/supplemental-handbook-guidance

Pailler, M. E., Cronholm, P. F., Barg, F. K., Wintersteen, M. B., Diamond, G. S., & Fein, J. A. (2009). Patients' and Caregivers' Beliefs About Depression Screening and Referral in the Emergency Department. *Pediatric Emergency Care, 25*(11), 721-727.

Pelkonen, M. & Marttunen, M. (2003). Child and adolescent suicide: epidemiology, risk factors, and approaches to prevention. *Paediatric Drugs* **5**(4):243–65.

Pescosolido, B. A. (1992). Beyond rational choice: The social dynamics of how people seek help. *American journal of sociology*, *97*(4), 1096-1138.

Pidgeon, N., & Henwood, K. (1996). Grounded Theory: Practical Implementations. In Richardson, JTE (ed.) *Handbook of Qualitative Research Methods for Psychology and the Social Sciences*. *BPS Blackwell*.

Pine, D. S., Cohen, P., Gurley, D., Brook, J., & Ma, Y. (1998). The risk for early-adulthood anxiety and depressive disorders in adolescents with anxiety and depressive disorders. *Archives of general psychiatry*, *55*(1), 56-64.

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.

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme Version, 1*, b92.Prior, S. (2012). Young people's process of engagement in school counselling. *Counselling and Psychotherapy Research, 12*(3), 233-240.

Prior, S. (2012). Young people's process of engagement in school counselling. *Counselling and Psychotherapy Research*, *12*(3), 233-240.

Rachman, S. (1977). The conditioning theory of fearacquisition: A critical examination. *Behaviour research and therapy, 15* (5), 375-387.

Rapee, R. M. (2002). The development and modification of temperamental risk for anxiety disorders: Prevention of a lifetime of anxiety?. *Biological psychiatry, 52*(10), 947-957.

Rapee, R. M. (2012). Family factors in the development and management of anxiety disorders. Clinical child and family psychology review, Vol. 15, Issue 1, p. 69-80.

Reardon, T., Harvey, K., Baranowska, M., O’Brien, D., Smith, L., & Creswell, C. (2017a). 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*, 1-25.

Reardon, T., Harvey, K., Young, B., O’Brien, D. & Creswell, C. (2017b). Barriers and facilitators to parents seeking and accessing professional help for anxiety disorders in children: qualitative interview study. Manuscript submitted for publication, Department of Psychology, University of Reading, Berkshire, UK.

Reinharz, S. (1997). Who am I? The need for a variety of selves in the field. *Reflexivity and voice*, 3-20.

Rickwood, D., Deane, F. P., Wilson, C. J., & Ciarrochi, J. (2005). Young people’s help-seeking for mental health problems. *Australian e-journal for the Advancement of Mental health, 4*(3), 218-251.

Rickwood, D. J., Deane, F. P., & Wilson, C. J. (2007). When and how do young people seek professional help for mental health problems? *Medical Journal of Australia, 187*(7), S35-S39.

Rickwood, D., Mazzer, K. & Telford, N. (2015). Social influences on seeking help from mental health services, in-person and online, during adolescence and young adulthood. BMC Psychiatry 15:40. DOI 10.1186/s12888-015-0429-6.

Rosenstock, I. M. (1966). Why people use health services. Milbank Quarterly, 44, 94–106.

Rosenstock, I. M. (1974). Historical origins of the health belief model. Health Education Monograph, 2, 328–335.

Silverman, W. K., & Albano, A. M. (1996). *Anxiety Disorders Interview Schedule for DSM-IV.: Child interview schedule* (Vol. 2). Graywind Publications.

Silverman, W. K., Saavedra, L. M., & Pina, A. A. (2001). Test-retest reliability of anxiety symptoms and diagnoses with the Anxiety Disorders Interview Schedule for DSM-IV: child and parent versions. *Journal of the American Academy of Child & Adolescent Psychiatry*, *40*(8), 937-944.

Simpson, D., Suarez, L., & Connolly, S. (2012). Treatment and outcomes for anxiety disorders among children and adolescents: A review of coping strategies and parental behaviors. *Current psychiatry reports*, *14*(2), 87-95.

Smith, J.A. (1996). Evolving issues for qualitative psychology. JTE (Ed) *Handbook of Qualitative Research Methods for Psychology and the Social Sciences*, Leicester, BPS Books.

Sonuga-Barke, E. J., & Balding, J. (1993). British parents' beliefs about the causes of three forms of childhood psychological disturbance. *Journal of abnormal child psychology, 21*(4), 367-376.

Spence, S. H. (1998). A measure of anxiety symptoms among children. *Behaviour research and therapy, 36*(5), 545-566.

Spence, S. H., Barrett, P. M., & Turner, C. M. (2003). Psychometric properties of the Spence Children's Anxiety Scale with young adolescents. *Journal of anxiety disorders*, *17*(6), 605-625.

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*(2), 618-630.

Stein, D. J., Phillips, K. A., Bolton, D., Fulford, K. W. M., Sadler, J. Z., & Kendler, K. S. (2010). What is a mental/psychiatric disorder? From DSM-IV to DSM-V. *Psychological medicine, 40*(11), 1759-1765.

Steinberg, L., & Silk, J. S. (2002). Parenting adolescents. *Handbook of parenting*, *1*, 103-133.

Thirlwall, K., Cooper, P. J., Karalus, J., Voysey, M., Willetts, L., & Creswell, C. (2013). Treatment of child anxiety disorders via guided parent-delivered cognitive-behavioural therapy: randomised controlled trial. *The British Journal of Psychiatry*, *203*(6), 436-444.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol, 8*. doi:10.1186/1471-2288-8-45

Timlin-Scalera, R. M., Ponterotto, J. G., Blumberg, F. C., & Jackson, M. A. (2003). A grounded theory study of help-seeking behaviors among white male high school students. *Journal of Counseling Psychology, 50*(3), 339-350. doi:10.1037/0022-0167.50.3.339

Waite, P., & Creswell, C. (2014). Children and adolescents referred for treatment of anxiety disorders: Differences in clinical characteristics. *Journal of affective disorders*, *167,* 326-332.

Warwick, H., Reardon, T., Cooper, P., Murayama, K., Reynolds, S., Wilson, C., & Creswell, C. (2017). Complete recovery from anxiety disorders following Cognitive Behavior Therapy in children and adolescents: A meta-analysis. *Clinical Psychology Review*, *52*, 77-91.

Weisz, J.R., McCarty, C.A. & Valeri, S.M. (2006). Effects of psychotherapy for depression in children and adolescents: a meta-analysis. Psychological Bulletin 132(1):132–49.

Whiteside, S. P., & Brown, A. M. (2008). Exploring the utility of the Spence Children's Anxiety Scales parent-and child-report forms in a North American sample. *Journal of Anxiety Disorders*, *22*(8), 1440-1446.

Willig, C. (2013). *Introducing qualitative research in psychology*. McGraw-Hill Education (UK).

Wilson, C. J., & Deane, F. P. (2001). Adolescent opinions about reducing help-seeking barriers and increasing appropriate help engagement. *Journal of Educational and Psychological Consultation, 12*(4), 345-364. doi:Doi 10.1207/S1532768xjepc1204_03

Wisdom, J. P., Clarke, G. N., & Green, C. A. (2006). What Teens Want: Barriers to Seeking Care for Depression. *Administration and Policy in Mental Health and Mental Health Services Research, 33*(2), 133. doi:10.1007/s10488-006-0036-4

Wolk, C. B., Kendall, P. C., & Beidas, R. S. (2015). Cognitive-behavioral therapy for child anxiety confers long-term protection from suicidality. *Journal of the American Academy of Child & Adolescent Psychiatry, 54*(3), 175-179.

Woodward, L. J., & Fergusson, D. M. (2001). Life course outcomes of young people with anxiety disorders in adolescence. *Journal of the American Academy of Child & Adolescent Psychiatry*, *40*(9), 1086-1093.

World Health Organization. (2002). *The world health report 2002: reducing risks, promoting healthy life*. World Health Organization.

Yardley, L. (2015). Demonstrating validity in qualitative psychology. In Smith, J. A. (Ed.). (2015). *Qualitative psychology: A practical guide to research methods*. Sage.

Zwaanswijk, M., van der Ende, J., Verhaak, P.F., Bensing, J.M. & Verhulst, F.C. (2003). Factors associated with adolescent mental health service need and utilization. *Journal of the American Academy of Child and Adolescent Psychiatry*. 42:692–700.