

“Just keep pushing”: parents’ experiences of accessing child and adolescent mental health services for child anxiety problems

Article

Accepted Version

Crouch, L., Reardon, T., Farrington, A., Glover, F. and Creswell, C. (2019) “Just keep pushing”: parents’ experiences of accessing child and adolescent mental health services for child anxiety problems. *Child: Care, Health and Development*, 45 (4). pp. 491-499. ISSN 1365-2214 doi: 10.1111/cch.12672 Available at <https://centaur.reading.ac.uk/83295/>

It is advisable to refer to the publisher’s version if you intend to cite from the work. See [Guidance on citing](#).

To link to this article DOI: <http://dx.doi.org/10.1111/cch.12672>

Publisher: Wiley

All outputs in CentAUR are protected by Intellectual Property Rights law, including copyright law. Copyright and IPR is retained by the creators or other copyright holders. Terms and conditions for use of this material are defined in the [End User Agreement](#).

www.reading.ac.uk/centaur

CentAUR

Central Archive at the University of Reading

Reading's research outputs online

“Just keep pushing”: parents’ experiences of accessing child and adolescent mental health services for child anxiety problems

Abstract

Background: Anxiety disorders are among the most common psychopathologies in childhood, however a high proportion of children with anxiety disorders do not access effective treatments. The aim of the present qualitative study was to understand families’ experiences of seeking help and accessing specialist treatment for difficulties with childhood anxiety.

Methods: Parents of 16 children (aged 7-12 years) referred to a child mental health service for difficulties with anxiety, were interviewed about their experiences of seeking and accessing treatment within CAMHS. All interviews were transcribed verbatim and thematically analysed for similarities and differences in families’ experiences.

Results: Factors that helped and/or hindered families accessing treatment related to: i) parental recognition, ii) contact with professionals, iii) reaching CAMHS, iv) parental effort, and v) parental knowledge and concerns. High demands on services and parents’ uncertainty surrounding the help-seeking process presented key hurdles for families. The critical role of parental persistence and support from GPs and school staff was evident across interviews.

Conclusions: Findings highlighted the need for information and guidance on identifying child anxiety difficulties and professional, peer and self-help support; and ensuring sufficient provision is available to allow families prompt access to support.

1. Introduction

Anxiety disorders are the most common mental health disorders experienced by children and adolescents (Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015), with a median age of onset of 11 years (Kessler et al., 2005). Left untreated, anxiety in childhood often continues into adolescence and adulthood (Bittner et al., 2007), and is associated with poor social, health and occupational outcomes (Copeland, Angold, Shanahan, & Costello, 2014; Essau, Lewinsohn, Olaya, & Seeley, 2014), and substantial economic burden (Fineberg et al., 2013). Effective treatments for child anxiety disorders exist, but it is widely reported that only a minority of children with mental health disorders access treatment (Green, McGinnity, Meltzer, Ford, & Goodman, 2005; Merikangas et al., 2011). Moreover, lower rates of treatment access are reported for anxiety disorders compared to behavioural disorders in children (Merikangas et al., 2011). A recent UK survey reported that only 38.4% of children with anxiety disorders receive support from professionals, and an even smaller minority (15.2%) receive support from specialist mental health services (Reardon, Harvey and Creswell, under review).

Parents play a ‘gatekeeper’ role in accessing mental health treatment for children (Stiffman, Pescosolido, & Cabassa, 2004), and are instrumental in recognising a child’s difficulties, deciding to seek help, and successfully obtaining treatment within specialist child mental health services (Logan & King, 2001). Indeed, parental recognition of a child’s difficulties is associated with a child’s use of specialist mental health services (Teagle, 2002; Sayal et al., 2010), and parents typically contact or seek help from a range of professionals prior to their child receiving support (Reid et al., 2011; Shanley, Reid, & Evans, 2008). Furthermore, GPs are more likely to recognise a child’s difficulties and refer a child to a specialist mental health service if a parent raises concerns about their child, or requests a

referral for their child, than in the absence of parental concern or referral requests (Sayal, 2006; Sayal, Taylor, Beecham, & Byrne, 2002). Given this key role parents play in a child's access to mental health treatment, gaining insight into parents' experiences of accessing specialist mental health services in the context of child anxiety, could help identify key areas for intervention to address the low rates of treatment access among this population.

Parents experience a broad range of barriers to accessing treatment for child mental health difficulties, including systemic issues associated with services (e.g. referral criteria, demand on services), parents' attitudes towards services, parents' knowledge and understanding of mental health help-seeking, and family circumstances (Reardon et al., 2017). Barriers parents face accessing specialist child mental health services in the context of anxiety difficulties in children, however, are less well understood. A recent qualitative study examining experiences of seeking help among parents of children identified as having anxiety disorders in the community, illustrated barriers families face recognising the anxiety difficulty, recognising the need for professional support, contacting professionals, and receiving support from professionals (Reardon, Harvey, Young, O'Brien, & Creswell, 2018). However, as families in this study were recruited in the general community, many participating families had not received any professional support, and only a minority had reached specialist mental health services. Gaining insight into the experiences of families who have successfully reached specialist mental health services for anxiety difficulties in children, will contribute further to identifying factors that help and hinder families throughout their journey towards successfully accessing these services.

1.1. Aims of the present research

This study adopted an inductive qualitative approach to explore help-seeking among parents of children (aged 7-12 years) who have accessed a specialist mental health service for their child's difficulties with anxiety. Specifically, the study aimed to identify factors that

help and hinder access to specialist mental health services for anxiety difficulties in children. Given that anxiety disorders typically first appear before age 12 (Kessler et al., 2005), and parents' and a young person's role in the help-seeking process may change as a child gets older, we focused on help-seeking among parents of pre-adolescent children.

2. Methods

2.1. Participants

Participants were parents/legal guardians of 16 children aged between 7-12 years old, referred to Berkshire Healthcare NHS Foundation Trust's Child and Adolescent Mental Health Service (CAMHS) for difficulties with anxiety. A purposive sampling approach was used to help ensure parents with varied views and experiences related to seeking help for their child were recruited (Robinson, 2014). Families invited to take part varied in relation to: i) the child's age and gender ii) the type of anxiety difficulty; iii) the presence of comorbid difficulties; iv) their stage in the process of accessing treatment, from recent referral to CAMHS through to completed treatment.

Parents of 34 children were invited to take part in the study, and parents of 19 children agreed to participate. Interviews were arranged and conducted with parents of 16 children, at which point theoretical saturation was reached (Sandelowski, 1995). To ensure the detailed analysis of the full dataset was feasible, no further interviews were conducted. Participant details are provided in Table 1. Interviews were conducted with parents of 6 girls, and 10 boys, with a median child age of 10.6 years. The majority of parents were female ($n = 14$), and White British ($n = 13$), with 9 families categorised as higher/professional. Children were referred to CAMHS for difficulties with varied types of anxiety, including specific fears and worries, separation anxiety, panic attacks, situation specific anxieties, and generalised anxiety. Child anxiety symptoms and associated level of impairment varied across the

sample, and Spence Children's Anxiety Scale-Parent Version (SCAS-P) scores all indicated elevated anxiety, and ranged from 31 to 69 (mean 48.6; SD 13.0), and Child Anxiety Impact Scale-Parent Version (CAIS-P) scores ranged from 17 to 46 (mean 32.0; SD 10.1). Comorbid difficulties reported by parents included: obsessive compulsive disorder ($n = 2$), speech and language difficulties ($n = 2$), post-traumatic stress disorder ($n = 1$), traumatic brain injury ($n = 1$), dyslexia ($n = 2$), autism/Asperger's ($n = 4$), and physical health conditions ($n = 5$). One family were waiting for an initial assessment with CAMHS, 4 were waiting to start treatment, 7 were currently receiving treatment, and 4 had completed treatment. Families who were receiving or had completed treatment, had all received a brief parent-led cognitive behavioural therapy ($n = 11$).

[Insert Table 1 here]

2.2. Procedure and data analysis

The study was approved by the NHS East Midlands – Leicester Central Research Ethics Committee (██████████) and University of Reading Research Ethics Committee (██████████). All participants provided written informed consent before participating in the study and were given a £10 voucher to reimburse them for their time.

Parents completed and returned questionnaires by post prior to the interview (SCAS-P, CAIS-P and demographic questionnaire). In depth semi-structured topic guided interviews were conducted with parents on the telephone and lasted an average of 37 minutes. The interviews explored: i) recognition of the child's difficulties with anxiety; ii) parents' experiences of seeking both informal and formal help; iii) support families sought and received from different professionals; and iv) families' experiences of accessing CAMHS. All interviews were audio-recorded and transcribed verbatim. All information that could identify participants was removed at the point of transcription, and names were replaced with pseudonyms.

Coding and analysis were led by one researcher (■■■) using a thematic analysis approach (Braun & Clark, 2006). Transcribed interviews were coded using line by line coding, and Nvivo 11 was used to facilitate this process. As each transcript was coded, new codes were generated, and previous codes were revisited, reviewed, and refined. The lead researcher regularly met with team members (■■■■■) to discuss codes and emerging themes, giving particular attention to alternative potential interpretations of the data. This process ensured precise use of labels and definitions, and clear identification and boundaries for each theme and subtheme (Boyatzis, 1998).

2.3. Measures

Spence Children's Anxiety Scale-Parent Version (SCAS-P). The SCAS-P (Nauta, et al., 2004) is a widely used parent-report questionnaire measure of symptoms of DSM anxiety disorders in children, with good evidence in support of its reliability and validity (Arendt, Hougaard, & Thastum, 2014; Nauta et al., 2004). It consists of 38 items, rated on a 4-point scale (never – always), and includes items addressing symptoms of generalised anxiety (6 items), social phobia (6 items), separation anxiety (6 items), panic/agoraphobia (9 items), obsessive compulsive behaviour (6 items), and physical injury fears (5 items).

Child Anxiety Impact Scale-Parent Version (CAIS-P). The CAIS-P is a parent-report questionnaire measure of impairment associated with a child's anxiety symptoms, with strong psychometric properties (Langley, Bergman, McCracken, & Piacentini, 2004; Langley et al., 2014). It includes 27 items rated on a 4-point scale (not at all – very much), and includes items related to impairment in relation to home/family activities, school activities, and social activities. Two items considered not appropriate for pre-adolescent children were omitted (going on a date, having a boyfriend/girlfriend).

3. Results

Findings are presented in relation to five main themes: i) parental recognition, ii) contact with professionals, iii) reaching CAMHS, iv) parental effort, and v) parental knowledge and concerns. As detailed below, a number of factors were identified in relation to each theme that helped and/or hindered families in the process of accessing specialist mental health treatment for their child's anxiety difficulties.

3.1. Parental recognition

Child's difficulties. Parents experienced difficulties identifying their child's problems as symptoms of anxiety and not other behavioural or psychological issues: *"I don't think there are very many people who can associate this sort of behaviour with anxiety. Often it will come across as disruptive behaviour."* (Parent 1). The presence of comorbidities also often hindered parents' abilities to recognise their child's symptoms of anxiety: *"I thought it was just all the autism thing really, I was not sure what it was."* (Parent 2). One parent described the complications associated with her child's comorbid difficulties as a barrier to seeking support for his anxiety difficulties: *"It's been a longer process because we've had to deal with his medical situations, the brain injury... the delay in getting to the GP was mostly because I was caring for my son."* (Parent 3).

Family and friends. Discouragement or dismissal from family and friends sometimes deterred parents from seeking professional help: *"My friend's husband said he can't be [anxious or depressed], so I just kind of brushed it off."* (Parent 15). It was clear that parents also compared their child who experienced difficulties with anxiety to other children and siblings, and in some cases, this helped prompt parents' recognition and help-seeking: *"It was becoming more and more apparent that there were differences between him and his peer group."* (Parent 7); *"I've got older children, so I knew that something wasn't right."* (Parent 4). One parent also referred to the challenges associated with having two children with anxiety difficulties, and the negative impact this had on seeking support for each child:

“When you have two children suffering from the same problem, if you start encouraging one to talk about it and the other one isn’t ready, it becomes counterproductive.” (Parent 3).

Delay. Parents often described a long delay in recognising their child’s need for professional support. In some cases, parents felt their child had always been anxious, and this made it hard for them to decide when their child needed help. Parents appeared to wait until they were most in need of help or at a crisis point, before seeking help: *“You put up with it for a long time and then there’s a point when you break... when you refer yourself to CAMHS or to anybody you waited till the last minute, till you can’t cope.”* (Parent 13).

3.2. Contact with professionals

GP. Parents described their contact with a GP as a positive experience. In particular, parents referred to feeling listened to by GPs, and felt their GP had taken their concerns seriously, trusted their judgement, and showed empathy: *“He acts on [my concerns] straight away and that’s probably because he knows that I know when [my child’s] got a problem”.* (Parent 2); *“It was nice that someone saw the problems he had and actually took them seriously.”* (Parent 5). Some parents also felt that it was important that their GP recognised that their child needed support; but also reassured them that it is not uncommon for children to experience problems with anxiety: *“[The GP] said it’s okay we’ve seen this before, you’re not on your own, there is help. It was really reassuring.”* (Parent 15). Parents referred to quick responses and referrals from GPs as another helpful factor: *“The doctor was brilliant, she referred me straight away.”* (Parent 15), and highlighted GPs’ ability to differentiate between comorbid physical and mental health difficulties as important: *“He’s had his nausea, he’s now got a [sick] phobia...we went to the GP because he had a lump in his throat, he can’t swallow again... to see that there wasn’t actually anything wrong with him and he’s got some medication for acid [reflux].”* (Parent 5).

School staff. School staff recognising and acting on a child's anxiety difficulties played a helpful role in parental help-seeking. This included children gaining support within school, and being referred to and accessing specialist mental health services: *"School are really good, they really do acknowledge that he's got problems and they do try and help him."* (Parent 2); *"I went into school and they did a referral, so that's where it all began."* (Parent 9). Parents who felt at ease approaching and speaking to school staff, often sought initial help or advice from teachers: *"It was quite easy to talk to his teacher, the SENCO, and headteacher, so I think they were very supportive."* (Parent 14). Parents who had trusting relationships with school staff also followed their advice, which in some cases prompted visits to the GP and a referral to CAMHS: *"[The teacher said] if you feel like you're not managing it, go to the doctors... I hadn't even thought this was something to go to the doctor about before she said that."* (Parent 15). Some parents, however, described that school staff did not recognise their child's difficulties with anxiety: *"Alex's [anxiety] is such a silent thing and they say he's absolutely fine, they don't really believe it."* (Parent 5); *"We did bring it up with the school on lots of occasions... but no one believed us because it never happened at school."* (Parent 13). A lack of recognition among school staff delayed treatment access for some families: *"CAMHS wrote back and said your GP can't refer you we've got to go back through the school and then we waited another six months trying to get school on board."* (Parent 14).

Other professionals. Where a child had comorbid physical or mental health difficulties, other health professionals involved in supporting the child were often a first point of contact for parents: *"So first of all I contacted [the autism worker], I knew she was my first call of contact."* (Parent 2). In some cases, contact with other health professionals helped facilitate the family's access to CAMHS: *"[The paediatrician] then decided that she would do another referral... and that referral has been more successful."* (Parent 3).

3.3. Reaching CAMHS

Meeting service criteria. Some parents described that in the past their child had failed to meet the criteria that was required to access treatment within CAMHS. These parents felt that their child's difficulties needed to tick certain boxes, and this resulted in unsuccessful referrals and delayed access to treatment: *"She wasn't ticking all the boxes for all the criteria... she was ticking boxes across everything, but not enough in each box."* (Parent 4).

Waitlist. Unsurprisingly, waitlists delayed families' access to treatment. One parent described that the nature of her child's anxiety had changed whilst waiting, and by the time the family received treatment, it was not helpful: *"When we finally came to have the treatment he basically was over it... so it was a bit of a waste."* (Parent 5). The long wait to start treatment prompted some parents to seek private support for their children *"I did take on a private psychologist at one point because CAMHS is just too long to wait."* (Parent 13); and parents who had completed treatment within CAMHS referred to waiting times as a reason to seek professional support from elsewhere in the future: *"We wouldn't go for a re-referral because of the [waitlist] time."* (Parent 5). One parent suggested that providing an opportunity for parents to meet other parents while waiting to access treatment, would allow families to benefit from this form of peer support sooner: *"You could get in contact I suppose with other parents... in that time... more parent to parent support before you get seen."* (Parent 9).

Contact with clinicians. Many parents described the contact they had with clinicians during initial assessments, the waitlist period, and during treatment as positive experiences: *"She was giving me strategies to try with Lily [during the waitlist period] until I'd had any more information about the course."* (Parent 9). Parents also referred to the importance of clinicians making the parent and child feel calm and comfortable during the initial

assessment, and the positive impact this had on the family's perceptions of subsequent treatment sessions: *"It was very open, we all felt very relaxed in that we could be emotional. It was a really nice environment."* (Parent 13); *"When I told her we had to go back she was actually looking forward to it."* (Parent 9). Parents referred to clinicians recommending resources and materials during a child's initial assessment, and this helped parents feel prepared for treatment, and prompted some to seek further self-help support: *"Before I went on the CBT course I'd already read the book... and it was very useful."* (Parent 13); *"She said to me that I could go on certain websites and find out information which is what I did."* (Parent 2). Some parents also described reusing materials when their child's anxiety symptoms resurfaced or changed following treatment, and consequently felt they did not need to seek further professional help. Several parents emphasised the importance of contact with professionals during the waitlist period: *"That is the really hard prime bit when you feel very much alone."* (Parent 13), and commented that contact from a professional while waiting for treatment would make the waiting process easier: *"Just a mid-wait call to ring up and say 'I'm just touching base with you again, this is what we expect to be the period of time that you'll now need to wait'."* (Parent 1).

Administrative and non-clinical issues. Some parents referred to administrative issues as presenting hurdles in the process of accessing treatment. One parent identified appointment and information letters as barriers to treatment access, because they felt they were difficult to understand: *"[The forms] are not straight forward... is something that's going to put people off."* (Parent 12).

Funding and resources. Parents expressed empathy for CAMHS staff and referred to the pressure they are under to support the increasing number of children accessing CAMHS for anxiety difficulties: *"More and more children are being diagnosed with these things, but there aren't the finances there to give the support that is needed for the staff."* (Parent 4).

Most parents believed the long waiting times and difficulties they had encountered trying to access treatment within CAMHS, were due to an overarching lack of government funding and resources: *“The problem is a central one, it’s all about funding and that’s primarily why the waiting lists are so long, because there isn’t enough staff and the staff are restricted due to funding.”* (Parent 3); *“Getting in to the circuit is really hard work because of the lack of resource. It’s just underfunded and there’s not the capacity there.”* (Parent 12).

3.4. Parental effort

Managing the anxiety. Parents described various ways that they tried to help their child manage their anxiety difficulties. Parents referred to finding out about strategies to use at home, before seeking professional help: *“I thought, there’s no point getting any professional help if we can try and manage it, I did look into CBT and tried it.”* (Parent 15). One parent attended workshops and courses to learn ways to help their child overcome their symptoms: *“I had started working on everything I possibly could, so I had been on [a workshop], I’ve had a mindfulness course to help him, there were a whole list of things.”* (Parent 14). Another parent referred to an intention to organise a support group in the local community for families with children with OCD: *“I wondered whether I could organise a local sort of OCD [children’s group].”* (Parent 15).

Persistent help-seeking. The majority of parents described *chasing, fighting or pushing* to gain access to support. Persistent and repeated contact with professionals, such as GPs and teachers, sometimes prompted these professionals to contact specialist services: *“We got other people to listen to us through school... [school staff] did start contacting CAMHS to say we really need some help.”* (Parent 13). Similarly, professionals also advised parents to *chase* services themselves: *“[The legal professionals] are saying you must still chase the NHS... see if you can get him up on the waiting list.”* (Parent 3). It was clear that most parents felt parental persistence was needed to access support, and to speed up accessing

treatment: *“Just keep pushing...keep phoning, keep on at the doctor until you do get [the support].”* (Parent 4); *“School asked me to chase it up so I did, then the next thing I know I’ve got an appointment come through.”* (Parent 2).

3.5. Parental knowledge and concerns

Uncertainty. Many parents expressed uncertainty about a variety of topics, including, how long they would have to wait to access treatment, and how best to support their child during this waitlist period: *“I was a bit anxious about how long it would all take... and I still don’t know.”* (Parent 1); *“You’re just left in limbo because you’re not sure... am I saying the wrong thing, am I making it worse.”* (Parent 9). Some parents who had completed treatment were uncertain about who to contact for help if their child’s symptoms resurfaced: *“I’m not sure how to deal with it if we aren’t doing good... am I completely discharged from CAMHS, do I have a contact... I don’t actually know.”* (Parent 13). Feeling uncertain prevented and delayed parents from making decisions, and this restricted some families’ access to support: *“The school were saying ‘what can we do to support’ and I was like ‘I don’t know.’”* (Parent 9). Some parents also felt they had to make decisions and seek help without all the necessary information: *“It’s a leap of faith because you’re engaging with an organisation you know very little about, so it’s making that choice without having all the information.”* (Parent 1).

Concerns. Parents who had completed treatment or were anticipating being discharged from CAMHS, expressed concerns around their ability to cope and the need for further support if their child’s anxiety resurfaced, increased, or was still present following treatment. These concerns were particularly apparent when a child was also receiving support or medication for other comorbid difficulties: *“I did say I’m uncomfortable discharging him because if they decide not to prescribe him [the medication], then we’ll be straight back on the pathway again.”* (Parent 14). Some parents also delayed seeking help due to concerns related to mental health stigma. One parent found it difficult to seek help from the GP

because they were concerned that their child's anxiety symptoms would be perceived as their fault: *"Admitting that your child has a mental health problem is obviously not an easy thing, because it's like what have we done to cause this."* (Parent 5). Some parents were also concerned that their children would be affected by mental health stigma in the future: *"Daniel's mother is very concerned that the issues don't get recorded in his NHS records because she feels that could have a prejudicial effect on his future employment prospects."* (Parent 12). This parent also felt that families who are influenced by mental health stigma may be less likely to seek help, and identified the importance of professional recognition in these cases.

4. Discussion

4.1. Main findings

Five key areas were identified that helped and hindered families to access specialist mental health services for child anxiety difficulties. In line with previous research (Reardon et al., 2018; Teagle, 2002), parents experienced challenges identifying their child's anxiety difficulties and differentiating between anxiety and other comorbid difficulties. Indeed, parents often delayed seeking help because they were unsure whether their child needed support or not. Parents reported seeking help and advice from a range of professionals, including GPs, school staff and other health professionals, and the critical role these professionals played in helping – or hindering – the family's access to further support was evident across interviews. Notably, all parents identified the key role that a GP's positive response played in facilitating the families' access to treatment. Indeed, families who have not received professional support report more varied experiences related to contact with GPs (Reardon et al., 2018) so it is likely that the consistently positive response from GP reported here is related to the fact that this sample had all successfully reached a specialist service. It

was also evident that where a child had comorbid physical or mental health conditions, other health professionals, such as paediatricians, were also often a critical first point of contact for parents. In keeping with reports of high demands on specialist child mental health services (Saxena, Thornicroft, Knapp, & Whiteford, 2007), parents referred to a failure to meet service criteria, and long waiting lists as preventing their child from receiving treatment promptly. Parents identified the importance of regular, clear communication with services during waiting periods and the benefit of access to other sources of support at these times (e.g., self-help materials, peer support, community support groups). The need for repeated contact with multiple professionals prior to receipt of child mental health services is reported elsewhere (Shanley et al., 2008), and the extent of parental effort and persistence throughout the help-seeking process was striking. It was also clear that uncertainty and concerns surrounding key elements of the help-seeking process, including where and when to seek help, what to expect from services, and possible negative consequences for their child, presented hurdles for families.

4.2. Implications

The study findings identify key areas for potential intervention and service improvement needed to increase access to treatment for children with anxiety difficulties. In particular, findings highlight the importance of raising awareness and understanding of anxiety difficulties in children among parents and the general population. Readily accessible information on the signs and symptoms of anxiety difficulties in children, and other common comorbid difficulties, including guidance on when a child may benefit from professional support, could help make it easier for parents to seek help at an early stage. Moreover, findings indicate the potential benefit of ensuring parents are aware of and can easily access available information and guidance on the help-seeking process, including information regarding when and where to seek help, the type of support offered by services, and guidance

on the benefits of available support that addresses concerns surrounding potential negative consequences of receiving mental health treatment.

The key role a range of health and education professionals can play in helping or hindering a family's access to child mental health services illustrates the need to ensure these professionals are equipped with sufficient knowledge and understanding to accurately identify anxiety difficulties in children, and where appropriate, to refer families to other professionals and services. Findings also highlight the importance of ensuring GPs, school staff and other health professionals, such as paediatricians, are able to develop trusting relationships with families and encourage and support parents to share concerns they may have about their child's anxiety. In addition to professional points of contact, the potential benefit of helping families to access other sources of support prior to reaching more specialist services was also clear. It is therefore particularly pertinent that GPs and school staff are aware of and can recommend self-help resources, peer support groups, and other national and local support organisations.

Findings surrounding parents' experiences of accessing a specialist child mental health service identify the importance of ensuring clear, regular communication between these services and families, as well as communication with other professionals (e.g. school staff, GPs) who are supporting these families. The detrimental impact of waiting for long periods prior to receiving treatment coupled with the 'fight' required to access these services evident across parents' experiences, highlights the need to ensure sufficient service provision is available for children with anxiety difficulties. Moreover, efforts to streamline the process and the steps involved in accessing specialist child mental health services would help ensure those families who would benefit from support reach these services in a timely manner.

4.3. Strengths and limitations

The inductive qualitative approach used in this study provided detailed insight into the experiences of families who had accessed a specialist mental health service for anxiety difficulties in pre-adolescent children, and explored factors that helped and hindered these families throughout their help-seeking journey. Purposive sampling allowed a range of views and experiences to be captured, and findings have clear implications for ways to address identified hurdles and improve access to treatment within a population where rates of treatment access are particularly low (Merikangas et al., 2011). Although diagnostic assessments were not used, SCAS-P scores were all in the elevated range (*t*-scores available from www.scaswebsite.com), and were comparable to scores reported in child anxiety disorder treatment trials (Thirlwall et al., 2013). It is also necessary however to acknowledge that the sample was recruited from one UK child mental health service, and given that services and routes to treatment access vary nationally and internationally, factors that help and hinder treatment access in other geographic settings may not have been captured. The sample were also predominantly White British, with limited variation in socio-economic status, and therefore it is likely that the views and experiences of families from different ethnic backgrounds and lower socio-economic background were not adequately captured. It will therefore be particularly important for future research to explore the experience of families from diverse ethnic and socio-economic backgrounds who seek and access specialist support for child anxiety difficulties.

Key Messages

- Providing families and professionals working with families (e.g. GPs, school staff, paediatricians) with information and guidance on identifying anxiety difficulties in children, would address key recognition barriers
- GPs, school staff and paediatricians need to be aware of and recommend self-help resources and other support services to families affected by child anxiety
- Child mental health services should ensure they have clear and regular communication with families they are supporting, including during waiting-periods

References

- 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.
- Bittner, A., Egger, H. L., Erkanli, A., Costello, E. J., Foley, D. L., & Angold, A. (2007). What do childhood anxiety disorders predict?. *Journal of Child Psychology and psychiatry*, 48(12), 1174-1183. doi:10.1111/j.1469-7610.2007.01812.x.
- 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.
- Copeland, W. E., Angold, A., Shanahan, L., & Costello, E. J. (2014). Longitudinal patterns of anxiety from childhood to adulthood: the Great Smoky Mountains Study. *Journal of the American Academy of Child & Adolescent Psychiatry*, 53(1), 21-33.
- Essau, C. A., Lewinsohn, P. M., Olaya, B., & Seeley, J. R. (2014). Anxiety disorders in adolescents and psychosocial outcomes at age 30. *Journal of affective disorders*, 163, 125-132. doi:10.1016/j.jad.2013.12.033.
- 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. doi:10.1177/0269881113495118.

- Green, H., McGinnity, Á., Meltzer, H., Ford, T., & Goodman, R. (2005). Mental health of children and young people in Great Britain, 2004.
- Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). 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. doi:10.1001/archpsyc.62.6.593.
- Langley, A. K., Bergman, R. L., McCracken, J., & Piacentini, J. C. (2004). Impairment in childhood anxiety disorders: Preliminary examination of the child anxiety impact scale–parent version. *Journal of Child and Adolescent Psychopharmacology*, 14(1), 105-114.
- Langley, A. K., Falk, A., Peris, T., Wiley, J. F., Kendall, P. C., Ginsburg, G., ... & Piacentini, J. (2014). The child anxiety impact scale: examining parent-and child-reported impairment in child anxiety disorders. *Journal of Clinical Child & Adolescent Psychology*, 43(4), 579-591. doi:10.1080/15374416.2013.817311.
- Logan, D. E., & King, C. A. (2001). Parental facilitation of adolescent mental health service utilization: A conceptual and empirical review. *Clinical Psychology: Science and Practice*, 8(3), 319-333.
- 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. doi:10.1016/j.jaac.2010.10.006.

- 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.
- 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. doi:10.1111/jcpp.12381.
- Reardon, T., Harvey, K., Baranowska, M., O'Brien, D., Smith, L., & Creswell, C. (2017). What do parents perceive are the barriers and facilitators to accessing psychological treatment for mental health problems in children and adolescents? A systematic review of qualitative and quantitative studies. *European child & adolescent psychiatry*, 26(6), 623-647. doi:10.1007/s00787-016-0930-6.
- Reardon, T., Harvey, K., & Creswell, C. (under review). Seeking and accessing professional support for child anxiety in a community sample.
- Reardon, T., Harvey, K., Young, B., O'Brien, D., & Creswell, C. (2018). Barriers and facilitators to parents seeking and accessing professional support for anxiety disorders in children: qualitative interview study. *European child & adolescent psychiatry*, 27(8), 1023-1031.
- Reid, G. J., Cunningham, C. E., Tobon, J. I., Evans, B., Stewart, M., Brown, J. B., ... & Shanley, D. C. (2011). Help-seeking for children with mental health problems: Parents' efforts and experiences. *Administration and Policy in Mental Health and Mental Health Services Research*, 38(5), 384-397. doi:10.1007/ s10488-010-0325-9.

- Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative research in psychology*, 11(1), 25-41.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in nursing & health*, 18(2), 179-183.
- Saxena, S., Thornicroft, G., Knapp, M., & Whiteford, H. (2007). Resources for mental health: scarcity, inequity, and inefficiency. *The lancet*, 370(9590), 878-889. doi: 10.1016/S0140- 6736(07)61239-2.
- Sayal, K. (2006). Annotation: Pathways to care for children with mental health problems. *Journal of Child Psychology and Psychiatry*, 47(7), 649-659. doi:10.1111/j.1469-7610.2005.01543.x.
- Sayal, K., Taylor, E., Beecham, J., & Byrne, P. (2002). Pathways to care in children at risk of attention-deficit hyperactivity disorder. *The British Journal of Psychiatry*, 181(1), 43-48.
- Sayal, K., Tischler, V., Coope, C., Robotham, S., Ashworth, M., Day, C., ... & Simonoff, E. (2010). Parental help-seeking in primary care for child and adolescent mental health concerns: qualitative study. *The British Journal of Psychiatry*, 197(6), 476-481. doi:10.1192/bjp.bp.110.081448.
- Shanley, D. C., Reid, G. J., & Evans, B. (2008). How parents seek help for children with mental health problems. *Administration and Policy in Mental Health and Mental Health Services Research*, 35(3), 135-146. doi:10.1007/s10488-006-0107-6.

Stiffman, A. R., Pescosolido, B., & Cabassa, L. J. (2004). Building a model to understand youth service access: The gateway provider model. *Mental health services research*, 6(4), 189-198.

Teagle, S. E. (2002). Parental problem recognition and child mental health service use. *Mental health services research*, 4(4), 257-266.

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. *British Journal of Psychiatry*, 203(6), 436-

444. Table 1

Participant characteristics

Participant ID	Parent			Child			Family SES	Comorbid conditions ^a	Referral source	Stage in CAMHS
	Age	Gender	Ethnicity	Age	Gender	Ethnicity				
1	45	female	WB	10	male	WB	higher/professional	stammer	GP	waiting for initial assessment
2	43	female	WB	12	male	WB	higher/professional	autism; epilepsy; OCD	GP	waiting to start treatment
3	45	female	WB	12	male	WB	higher/professional	brain injury; diabetes; PTSD	GP & Paediatrician	waiting to start treatment
4	48	female	WB	10	female	WB	other employed		Early years specialist service	waiting to start treatment
5	51	female	WB	11	male	WB	higher/professional	acid reflux	GP	completed treatment
6	-	male	-	-	male	-	-		-	currently receiving treatment
7	50	female	WB	11	male	WB	higher/professional	Asperger's	GP	currently receiving treatment
8	41	female	Indian	10	female	Indian	higher/professional	hypothyroidism	GP	currently receiving

9	34	female	WB	10	female	White & Asian	other employed		GP & school	ng treatment currently receiving treatment
10	39	female	WB	10	female	WB	other employed	dyslexia; learning difficulties; speech impairment	CAMHS	currently receiving treatment
11	43	female	WB	12	male	WB	other employed	dyslexia; asthma	NHS doctor	currently receiving treatment
12	60	male	WB	9	male	WB	Retired	Asperger's	School	currently receiving treatment
13	-	female	-	-	female	-	-			completed treatment
14	44	female	WB	11	male	WB	higher/professional	autism; asthma	School	completed treatment
15	35	female	WB	8	male	WB	higher/professional	OCD	GP	completed treatment
16	45	female	WB	10	female	WB	higher/professional		GP & school	waiting to start treatment

Note. WB=White British. SES=Socio-Economic Status. OCD=Obsessive compulsive disorder. PTSD=Post-traumatic stress disorder. CAMHS=Child and Adolescent Mental Health Service

a Comorbid conditions were self-reported by parents

