*Discussion Paper*

Preventing Anxiety Disorders: Improving Effectiveness of, and Access to, Programmes.

*The focus of this paper is the prevention of anxiety disorders in at risk children and how programmes might be made more effective and accessible to these children and their families. Child anxiety disorders are common, cause significant distress and predict the onset of other psychiatric disorders as well as educational under-attainment. Although effective treatments exist, barriers mean they are accessed by few and, for over 40% of those who do access them, are ineffective. Anxiety disorders can be prevented, particularly when children at risk are targeted, but prevention science is less well developed than treatment science, and barriers to prevention programmes have received almost no scientific attention. We are conducting a prospective natural history study of adolescents who, in infancy, were at risk of anxiety disorders, and a qualitative study to identify barriers to anxiety disorder prevention programmes and how to make them accessible to those at greatest risk.*

Anxiety disorders are common in children, adolescents and adults, with a median age of onset of 11 years of age and lifetime prevalence of 28.8%, making them one of the most common mental disorders throughout our lifespan (Kessler et al., 2005). They are associated with significant negative impacts in multiple domains of life, including later psychiatric illness (depression, psychosis, substance abuse); school drop-out, educational under-attainment, victimization by peers, and impaired life satisfaction (Bittner et al., 2007; Woodward & Fergusson, 2001).

 Cognitive Behaviour Therapy (CBT) is the most robustly examined treatment for anxiety disorders in children and young people. CBT can be done on a one to one basis, or in a group; either with the affected child, or with their parents, or some combination of these formats. It focuses on helping children, young people and their parents to develop skills to overcome the anxiety, in particular, the factors that maintain the anxiety disorder(s). This is done during and between sessions by testing out novel ways of thinking about the things that make them feel anxious, as well as trying new behaviours to see whether or not they help to overcome the anxiety.

A recent Cochrane review of CBT for anxiety disorders found that CBT is ineffective for a substantial minority of children and young people (James, James, Cowdrey, Soler, & Choke, 2015). Regarding treatment effectiveness, the Cochrane review found that CBT was more effective than wait list control (OR: 7.85, 95% CI = 5.31, 11.6); however, on average 41% of children remained anxious after treatment (James et al., 2015).

 A further concern regarding treatment of anxiety disorders is that there are significant barriers to access to treatment (Reardon et al., 2017). Between 30% and 40% of children with anxiety disorders in the USA and UK have gained access to treatment, and as few as 2.2% to an evidence based intervention (Reardon, Harvey, Young, O'Brien, & Creswell, 2018; Richardson, 2010). The reasons for low rates of access to treatment for young people with anxiety disorders are only beginning to be clarified, but include stigma, identification by parents of anxiety difficulties and structural barriers in services (Reardon et al., 2017; Reardon et al., 2018).

Prevention

Prevention of the development of ill health is a common feature of medical practice. In the UK, for example, a 6-in-one vaccine is given to children at age 8, 12 and 16 weeks of age to prevent the development of diphtheria, hepatitis B, Hib, polo, tetanus and whooping cough. Prevention is also a possible solution to the problems of the limited effectiveness of, and barriers to, treatment of anxiety disorders. First, it might be easier to intervene to modify risk factors before problems crystallize, than to treat disorders that have become entrenched (Donovan & Spence, 2000), meaning prevention mightbe more potent than treatment. Second, many of the sequelae of anxiety disorders in childhood, such as impaired school performance and peer victimization, occur once the disorder is established. Preventing the anxiety disorder might mitigate these negative child experiences. Third, it might be that some barriers to treatment, such as stigma, do not arise before the development of anxiety disorders. Without some of the barriers to treatment of anxiety disorders, prevention programmes might be more accessible than treatment programmes. Notably, prevention science is less well developed than treatment science and barriers to attending / engaging with anxiety disorder prevention programmes have, to our knowledge, received almost no attention in the literature.

Prevention of anxiety disorders

There is emerging evidence that targeted prevention programmes for children and young people identified as at risk of anxiety disorders are effective (Lawrence, Rooke, & Creswell, 2017). In light of prevention science being less well developed than treatment science, the mechanisms of effective targeted prevention are unclear. Putative mediators include altering the behaviours of parents that promote child anxiety, such as modelling anxious behaviours or verbally communicating that something is “too dangerous to go near”; modifying children’s anxious thoughts such as “It’s too scary for me to cope”, and reducing parents’ own anxiety. Furthermore, this targeted prevention could be more cost-effective than large-scale, universal prevention programmes, indiscriminately delivered to all children and young people (Stallard et al., 2014).

 Two of the most robust risk factors for anxiety disorders in children and adolescents are parent anxiety disorder (Micco et al., 2009) and child behavioural inhibition (BI), the temperamental characteristics of fear and withdrawal in novel situations (Degnan & Fox, 2007) . Parent anxiety disorders have been associated with a significantly increased risk of anxiety disorders in offspring relative to offspring of parents without psychiatric disorders (OR: 3.91, 95% CI = 2.51 – 6.1) and to offspring of parents with depression (OR: 1.84, 95% CI = 1.26 – 2.67) (Micco et al., 2009). BI has been prospectively associated with the broad class of anxiety disorders (Degnan & Fox, 2007) and social anxiety disorder in particular (OR: 7.59, 95% CI = 3.03 – 19.0) (Clauss & Blackford, 2012).

 There is accumulating evidence for the effectiveness of prevention programmes for children and young people at risk in light of parent anxiety disorders. In a recent meta-analysis, we found that, where children were identified as being at risk of developing an anxiety disorder in light of at least one of their parents having an anxiety disorder, targeted prevention programmes, compared to a wait list control group, led to a 91% reduction in risk of anxiety disorder onset at the end of the programmes, and a 69% reduction in risk of anxiety disorder onset one year after the programmes (Lawrence et al., 2017). A potentially crucial feature of the effective programmes used in these trials (‘Coping and Promoting Strength’, CAPS) was that parent anxiety disorder was addressed in the programme both in terms of being a trial inclusion criterion and a focus of the prevention programme itself (Ginsburg, 2009).

 Where children and young people have been identified as at risk of anxiety disorders on the basis of BI, we know of no programme which has included only children or young people *before* they develop an anxiety disorder; that is, no programme for children at risk in light of high BI has been purely preventive. However, a mixed secondary / tertiary prevention programme (‘Cool Little Kids’) has, been investigated for pre-school children identified on the basis of BI , of whom 90% had an anxiety disorder at baseline (Rapee, 2013). Rapee found that, 11 years after the programme (at approximately 15 years of age) females (but not males) who received the programme showed lower rates of internalizing disorders than those who did not receive the programme (Rapee, 2013).

 These studies have shown the promise of prevention programmes that identify children and young people at risk of anxiety disorders in light of parent anxiety disorder or in light of BI, and then address these modifiable risks within the programme components.

 Future examinations of prevention of anxiety disorders might target those at risk in light of *both* parental anxiety disorders *and* child BI. An early intervention programme for 3-4 year old children who had both these risk factors, but had already developed anxiety disorders, suggested it is possible to reduce anxiety severity and observed inhibited temperament (Kennedy, Rapee, & Edwards, 2009). To date, though, we know of no reports of disorder *prevention* programmes for children at risk in light of both of these risk factors. This is important because these two risk factors might interact to increase risk. For example, Ashford and colleagues examined the development of internalizing problems in children at 11 years, whom they had identified by 4 years with either no, one, or at least two risk factors (Ashford, Smit, Van Lier, Cuijpers, & Koot, 2008). Rates of internalizing problems at 11 years were 6.4% in those with no risk factors at 4 years, 15.5% where there had been one risk factor, but 48% in those with at least two risk factors. In the anxiety disorders in particular, Murray and colleagues found that mothers who had Social Anxiety Disorder showed more anxious parenting behaviours in a social situation than mothers without Social Anxiety Disorder, and that this predicted their 4 month old infants’ behaviour with strangers, *particularly* among those with high BI (Murray et al., 2008). We are now following up these same infants in their teenage years as part of a prospective natural history study of the intergenerational transmission of anxiety disorders, the ‘Reading Longitudinal Study’, to explore whether the early identified risk factors predict adjustment, including development of anxiety disorders, over fifteen years later.

Barriers to prevention

Barriers to engagement with and attendance at anxiety prevention programmes have received almost no attention in the literature. We do not know how many families who *would* be eligible for prevention programmes do not take part. We know of only a single study that has examined barriers to attending anxiety prevention (Cartwright-Hatton et al., under review). The study was conducted in the UK to assess the feasibility of a preventative programme targeting the intergenerational transmission of anxiety. The programme was a one day workshop for parents with anxiety disorders (a clinical sample, recruited from free-at-the-point-of-access adult mental health services). The authors found that, despite parents’ initial enthusiasm for the workshop, under 60% of parents randomly assigned to attend the workshop were able to attend. Reasons reported for this inability to attend included lack of childcare, inability to take time off work, travel difficulties, and anxiety about attending a group based session.

 In light of these results, examination of barriers and facilitators to prevention programmes is required to ensure prevention programmes are accessible and engaging for families. An initial step we are taking to address this gap is to conduct qualitative interviews with adolescent participants in the Reading Longitudinal Study who have developed anxiety disorders and, in infancy, had at least one risk factor (BI and / or maternal anxiety disorder) for developing an anxiety disorder. We will use the results to contribute to a prevention programme for offspring at risk of developing anxiety disorders in light of BI and / or parent anxiety disorders.

 In our qualitative study, we will address four issues to date unaddressed in the literature. First, whether adolescents who have developed an anxiety disorder and their parents would have *wanted* a prevention programme. For example, it might be that prevention is viewed as ethically premature – what if being identified as ‘at risk’ was itself a source of anxiety? What if a prevention programme was ineffective? Second, where participants tell us they would have wanted a prevention programme, when would they have wanted it? For example, before the emergence of even mild anxiety problems, once mild problems were emerging, or only once anxiety problems began to interfere in their lives? Third, for whom would they want the prevention to be made available? Some child anxiety treatment programmes are for children, some for only their parents, some for both children and their parents. What would they want for a prevention programme? Finally, what would make it accessible? For example, would a web-based programme be preferable, or a combination of face-to-face sessions with a web-based programme? Would it help if information were provided at nurseries / primary schools / GP surgeries?

Conclusion

Anxiety disorders are common in childhood, but can be treated. Two outstanding problems are the limited effectiveness of treatment, and that there are significant barriers to access to treatment. Prevention of anxiety disorders is possible, especially when targeting children at particular risk of developing anxiety disorders. The importance of exposure to *multiple* risk factors suggests that targeting children with more than a single risk factor for developing anxiety disorders might be more effective, but this has yet to be examined in a prevention programme. Barriers to access to anxiety disorder prevention programmes have received almost no attention in the literature. Future studies must examine what those who have developed anxiety disorders, *and* had early risk factors, would want a prevention programme to offer.

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**Correspondence:**

**Pete Lawrence**

NIHR Doctoral Research Fellow,

School of Psychology and Clinical Language Sciences,

University of Reading

p.j.p.lawrence@reading.ac.uk