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Feasibility study of a family-focused intervention to improve outcomes for children with FASD

Natasha Reid[a,*], Sharon Dawe[a], Paul Harnett[b], Doug Shelton[c], Lauren Hutton[a], Frances O'Callaghan[d]

[a] School of Applied Psychology, Menzies Health Institute Queensland, Griffith University, Mt Gravatt, Queensland, 4121, Australia
[b] School of Psychology, University of Queensland, St Lucia, Queensland, 4067, Australia
[c] Community Child Health, Child Development Service, Gold Coast Hospital & Health Service, Southport, Queensland, 4215, Australia
[d] School of Applied Psychology, Menzies Health Institute Queensland, Griffith University, Southport, Gold Coast, Queensland, 4215, Australia

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ABSTRACT

Background: Growing evidence shows that children with fetal alcohol spectrum disorder (FASD) can benefit from interventions, and specifically interventions focused on improving self-regulation. However, novel ways of improving outcomes for children with FASD need further investigation so that programs target not only the individual child but also the family context, which includes the parent–child relationship.

Aims: The current study aimed to evaluate the feasibility of an adapted version of the Parents under Pressure (PuP) program that addresses self-regulatory processes, through improving the parent–child relationship and the use of mindfulness-based strategies for both children and parents.

Methods: This was a mixed methods study. Feasibility was examined by evaluating recruitment, data collection/outcome measures, and intervention procedures. The study used a phenomenological approach to obtain qualitative information from caregivers and a single-case experimental design to evaluate the preliminary participant responses to the intervention.

Results: Two out of three families completed treatment. The recruitment and intervention procedures were found to be suitable for and acceptable to the families involved. Some concerns were identified regarding the outcome measures that would need to be addressed in future research. Quantitative and qualitative outcomes were positive.

Conclusions and implications: The results provide preliminary support for the feasibility of an adapted version of the PuP program. Thus, offering a potential multi-component option, that aims to improve self-regulatory skills for children with FASD, through focusing on improving the parent-child relationship and incorporating mindfulness-based techniques for both parents and children.

What this paper adds?

The current study provides preliminary evidence of an adaptation of a multi-component family-based intervention for children with FASD. The Parents under Pressure (PuP) program is a comprehensively evaluated program that focuses on improving self-regulation for children and parents, through the inclusion of mindfulness-based strategies and by improving the quality of the parent-

* Corresponding author at: School of Applied Psychology, Griffith University, 176 Messines Ridge Road, Mt Gravatt, Australia.
E-mail address: natasha.reid@griffithuni.edu.au (N. Reid).

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child relationship in families with complex needs. The current study assessed the feasibility of providing the PuP program for children with FASD. Both families that completed treatment reported that recruitment and intervention procedures were suitable and acceptable. Further, both families reported quantitative improvements in their child's level of psychosocial distress and qualitative improvements in the parent-child relationship.

1. Introduction

Fetal alcohol spectrum disorder (FASD) refers to the physical, cognitive, behavioural and/or learning disabilities that can be associated with prenatal alcohol exposure (Cook et al., 2016). While there is large variability in prevalence estimates (Roozen et al., 2016), evidence suggests that at least 2.4–4.8% of children in the United States have FASD (May et al., 2014). With substantially higher estimates for children in out-of-home care (e.g., Lange, Shield, Rehm, & Popova, 2013) and communities with high -levels of alcohol exposure (e.g., Fitzpatrick et al., 2015). The costs to society and individuals and their families are considerable. Thus, ongoing efforts to both prevent the occurrence of FASD and to ameliorate difficulties for those with FASD are essential.

Importantly, growing evidence suggests that children with FASD are able to benefit from interventions aimed at enhancing self-regulatory capacity (Reid et al., 2015). For example, benefits have been reported on the use of the ALERT program (Williams & Shellenberger, 1996), a 12-week manualised program that teaches children to recognise and change their arousal levels using sensory strategies, based on their current environmental needs. Three studies reported improvements in aspects of self-regulation, such as emotional problem-solving (Wells, Chasnoff, Schmidt, Telford, & Schwartz, 2012); inhibitory control and social cognition (Nash et al., 2015); parent-reported executive functioning skills in everyday life (Nash et al., 2015; Wells et al., 2012); and increases in cortical gray matter in regions underlying self-regulatory processes (Soh et al., 2015).

More recently, Kable, Taddeo, Strickland, and Coles (2016) conducted a pilot study that implemented Phase 1 of the GOFAR program. The broad goals of the program are to improve self-regulation skills using a computer program to teach problem-solving and adaptive life skills. In the GOFAR program, children are taught metacognitive learning strategies (e.g., Focus and Plan, Act and Reflect) to solve problems. Parents are provided with information about the metacognitive learning strategies and taught skills to manage children's heightened arousal states, in addition to behavioural management techniques. Children showed an improvement in their ability to sustain attention, with the effect more pronounced when parents received the same information as the children during the training and when they reported higher levels of engagement in the therapeutic process.

Consequently, previous interventions have focused on teaching children and parents mind-body awareness and sensory coping strategies (Nash et al., 2015; Soh et al., 2015; Wells et al., 2012) and/or metacognitive control strategies (Kable et al., 2016) to improve children's self-regulatory capacity. An additional approach to the enhancement of self-regulatory capacities is drawn from the growing literature on the incorporation of mindfulness-based strategies into psychological therapies for both adults (e.g., Khoury et al., 2013) and children (Harnett & Dawe, 2012; Kallapiran, Koo, Kirubakaran, & Hancock, 2015). Mindfulness training has been proposed as a method to improve self-regulation through improving top-down executive processes associated with frontal lobe structures, such as sustained attention and cognitive flexibility. At the same time, diminishing bottom-up influences associated with the limbic areas of the brain involved in the regulation of emotional arousal, such as stress or physiological dysregulation (Shapiro, Carlson, Astin, & Freedman, 2006; Zelazo & Lyons, 2012). Thus, we propose that a strong case can be made for the potential of mindfulness-based approaches to enhance self-regulatory capacities in children with FASD.

Furthermore, one of the proposed benefits of mindfulness meditation is that it produces a physiologically calmer state. (e.g., Burg, Wolf, & Michalak, 2012; Tang et al., 2009). This has been measured using respiratory sinus arrhythmia (RSA), a physiological measure of self-regulation. RSA refers to the observation that the intervals between successive heart beats (inter-beat intervals) are shorter during inspiration than during expiration (Beauchaine, 2015). Previous research with adults and our own research with children with FASD (Reid et al., under review) has found that RSA increased either during or following mindfulness practice (e.g., Burg et al., 2012; Tang et al., 2009). Higher values of RSA reflect greater variability in inter-beat intervals, which in turn has been found to be associated with more effective vagal control of emotional states in the face of environmental challenges (Beauchaine, 2015). Consequently, increasing RSA would be viewed as a positive outcome of therapy.

However, this would not necessarily be the case for children who continue to live in stressful home environments. As emerging research has demonstrated, higher RSA can actually be associated with more behavioural difficulties for children who are living in poverty and/or experiencing inconsistent caregiving (e.g., Conradt, Measelle, & Ablow, 2013). This may be due to children allocating additional attentional resources to monitor their unpredictable environment. Also, in the absence of a caregiver to promote self-regulatory skills, these children may develop maladaptive physiological mechanisms to regulate their emotional state, leading to emotional, behavioural, and physical health problems later in childhood (Conradt et al., 2016 Hostinar & Gunnar, 2013). Consequently, mindfulness training for children with FASD needs to be provided in conjunction with an intervention that aims to improve the quality of family functioning more generally. This is particularly important for children with FASD as they often live in families facing a range of psychosocial risk factors (Chamberlain, Reid, Warner, Shelton, & Dawe, 2017; Yumoto, Jacobson, & Jacobson, 2008).

Therefore, we are proposing an adaptation of the Parents under Pressure (PuP) program. The PuP program was developed as a home-based program for high-risk, vulnerable families. The program targets multiple domains of family functioning including: (i) the quality of the caregiving relationship; (ii) the parents' capacity to manage emotions and (iii) the broader ecological context in which the child is living. Consequently, the PuP program differs from previous interventions targeting self-regulation (i.e., Nash et al., 2015; Wells et al., 2012

The PuP program has a growing evidence base (e.g., Frye & Dawe, 2008; Harnett and Dawe, 2008 Harnett & Dawe, 2008), and has