

# **The Effects of Resourcefulness Training Intervention and Decentering on Self-Management of Stress in Caregivers of Children with Complex Chronic Conditions Dependent on Lifesaving Medical Technology**

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## **Abstract**

Parent caregivers of children who require life-saving medical technology such as mechanical ventilation or feeding tubes experience chronic stress that affects their overall physical and psychological health and compromises self-management behaviors and caregiving capacity. Our premise is that self-management interventions that target both analytic components and emotional components of self-management will be most effective in helping individuals achieve self-management outcomes. We are using fMRI to examine the relationship between two large-scale cortical networks, the default mode network (DMN) and the task positive network (TPN), and their contributions to behavior. Numerous studies have demonstrated that these networks may suppress each other, as measured both during task performance and in the resting state, which represents a marker of psychological health.<sup>1</sup> We interpret these findings as the ability to flexibly move between distinct cognitive modes associated with each network.<sup>2</sup> A key hypothesis is that effective tuning of DMN function is essential for effective TPN function, and in turn, optimal performance of self-management activities.

We hypothesize that Resourcefulness Training (set of self-help and help-seeking skills to control the effects of disturbing emotions, thoughts, and sensations on the performance of daily tasks)<sup>3</sup> and Mindfulness Training (to enhance decentering i.e., metacognitive capacity to observe thoughts, feelings, memories that arise in the mind with healthy psychological distance, greater self-awareness and perspective-taking)<sup>4,5</sup> facilitate the ability to shift between emotional neural processing (DMN) to analytic and task focused neural processing (TPN).<sup>6</sup> For caregivers of technology-dependent children, interventions that can facilitate shifting from emotional to analytic processing are hypothesized to yield greater self-management and better psychological and physical outcomes, enhancing the care they provide to others.

In this SMART Center randomized trial pilot study we will examine the effectiveness of a theoretically based intervention (called ReMind) encompassing two key components: (a) Resourcefulness Training (analytic TPN component) for parent caregivers, and (b) daily mindfulness meditation (emotion DMN component) delivered using a smartphone application (Stop, Breathe & Think™) with an intervention (Mind Only) that uses only the daily mindfulness meditation component. Both interventions can be self-tailored, which meets the vital need for these caregivers to engage in self-management activities when it is convenient for them. We will test the two arms of the intervention among 30 caregivers of technology-dependent children; 15 parents in each group. We will collect mixed methods data at baseline, 6 weeks, 3 months and 6 months after subject enrollment to describe changes in proximal and distal outcomes. We aim to:

1. Evaluate the short (6 week), intermediate (3 month) and long-term (6 month) effects of the ReMind and Mind Only interventions on study mediators (HPA Axis Function and stress, cognitive factors, resourcefulness) and determine if there are different effects between ReMind and Mind Only interventions.
2. Evaluate the differences in distal psychological (Mental HRQOL, Depressive Cognitions, Depressive Symptoms, Anxiety, Caregiver Burden), physical (Physical HRQOL), and cost outcomes between subjects in the ReMind and Mind Only arms over time.
3. Determine the moderating effects of parents' social support, demographics (age, gender, family income) and children's functional status on (a) proximal outcomes and the relationship between (a) the intervention arm and distal outcomes, and (b) HPA Axis Function, stress, cognitive factors and distal outcomes.
4. Evaluate the impact of decentering on the association between the interventions and the proximal and distal outcomes.
5. Explore differences in neuroprocessing (DMN and TPN) and decentering in proximal and distal outcomes associated with each intervention.

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