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Coping with the stress in the cardiac intensive care unit: Can mindfulness be the answer?

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ABSTRACT

Background: Mothers of infants with complex congenital heart disease are exposed to increased stress which has been associated with numerous adverse health outcomes. The coping mechanisms these mothers use critically effect the familial illness adaptation and most likely infant outcomes. Currently no data-based strategies have been developed for mothers to facilitate their coping, and proactively promote their adaptation in the critical care settings. A potential strategy is mindfulness which is currently used in other clinical settings with stress-reduction effects.

Purpose: (1) To investigate coping mechanisms of mothers whose infant with complex CHD is admitted in the CICU, and (2) to explore the acceptability and feasibility of mindfulness as a potential stress-reduction intervention for these mothers.

Design and Methods: A descriptive qualitative study obtained perspectives from 14 mothers during three focus groups. A qualitative conventional content analysis was performed using ATLAS.ti.

Results: In congruence with the Stress and Coping framework, themes identified mostly emotion-regulatory coping mechanisms including both active and passive strategies such as positive thinking, denial, distraction, relying on support systems, and focusing on baby. Mindfulness was an acceptable and feasible approach for most participants, however, practice unfamiliarity, time and space concerns, and personal preferences were identified as potential barriers for future dissemination.

Conclusions: Mindfulness can potentially promote illness adaptation by utilization of active coping mechanisms. Early interventions can provide immediate, and potentially long-term stress relief. Intervention settings, format, and time-frame should be flexibly tailored to the trajectory of parental distress and familial adjustment.

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Introduction

Approximately 32,000 infants are born with complex congenital heart disease (CHD) each year in the United States (Rosenberg et al., 2010), requiring life sustaining surgery before age one (Rychik et al., 2013). Mothers of those infants experience increased stress starting with their infant's diagnosis, surgery, and hospitalization in the cardiac intensive care unit (CICU). Stress lasts throughout infancy while caring for the infant at home (Hartman & Medoff-Cooper, 2012; Lisanti, Allen, Kelly, & Medoff-Cooper, 2017). Long-term maternal stress has implications on the health and well-being of the entire family, including adverse child outcomes. Increased stress in mothers of infants with CHD has been associated with anxiety, depression, and poorer quality of life; it has also been linked to the child's psychosocial adjustment and behavior problems (DeMaso et al., 1991; Hearps et al., 2014). The

mechanisms mothers use to cope with their stress have a crucial effect on the familial adjustment to the CHD (McCubbin & Patterson, 1983a, 1983b).

While in-hospital support systems are available, they primarily focus on treating communication issues between mothers and the health care team (Desai, Ng, & Bryant, 2002). Currently no reported systematic strategies helping mothers proactively manage the daily stress encountered during their infant's CICU stay were identified. One evidence-based strategy to manage stress is mindfulness. Mindfulness is a practice aiming to increase the individual's awareness and acceptance of daily experiences. Mindfulness, is currently used in a variety of healthcare settings and is regarded as a potentially effective skill for stress reduction, emotion, affect, and attention regulation (Khoury et al., 2013). The current study suggests that mindfulness may help mothers cope with the stress related to their neonate's hospitalization in the CICU, and with long-term adjustment to the complex CHD.

The purpose of the current study was to (1) qualitatively describe aspects of mothering an infant with complex CHD, including the strategies

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mothers use to cope with the stress in the CICU, and (2) to explore the acceptability and feasibility of mindfulness as a potential stress-reduction intervention for those mothers during their stay in the CICU. Effective coping strategies can promote parental adaptation to their infant's illness, improve their own physical and psychological health and well-being, and sustain a better quality of life for their families.

Background

Parental Adjustment to Complex CHD

CHD It is the most prevalent congenital anomaly occurring in approximately 1% of live births, and is the leading cause of death during infancy excluding prematurity (van der Bom et al., 2010). CHD includes more than 35 defects ranging in severity, prognosis, and long-term survival rates by disease complexity (Marino et al., 2012). Complex, life threatening defects, such as Hypoplastic Left Heart Syndrome, require early multi-staged surgical interventions followed by a lengthy hospitalization in the CICU (Marino et al., 2012). Parents of these infants experience increased stress around the timing of the CHD diagnosis, surgery, CICU stay, and discharge home (Dudek-Shriber, 2004; Hartman & Medoff-Cooper, 2012; Sarajuuri, Lonnqvist, Schmitt, Almquist, & Jokinen, 2012). Elevated stress is related to parental role alteration, infant's appearance, sights and sounds of the CICU, post-operative care, and potential complications (Carey, Nicholson, & Fox, 2002; Lisanti et al., 2017).

Stress influences parental adjustment, family processes, infant outcomes, and inhibits parents from processing informed decision-making regarding the infant's long-term care (Farley et al., 2007). Maladjustment to the infant's condition, parental role strain, poor quality of life and overall well-being predispose mothers to stress (Goldbeck & Melches, 2005; Miles, Carter, Hennessey, Eberly, & Riddle, 1989). Mothers are particularly vulnerable to stress during pregnancy, postpartum, and throughout infancy (Hartman & Medoff-Cooper, 2012). Unmanaged maternal stress is linked to poor behavioral adjustment in the child who has undergone neonatal cardiac surgery (Hearps et al., 2014).

Stress and Coping in the CICU

According to Lazarus and Folkman's (1984) Stress and Coping framework, illness-related stress appraisals and parental coping mechanisms eventually determine familial adjustment to the infant's CHD. Coping was defined by Lazarus and Folkman (1984) as the consistently changing mental or behavioral efforts to manage internal and external demands that are taxing or exceeding a person's resources. These efforts, or coping behaviors depend on both the individual's personality traits and the psychological appraisal of the stressor, which include personal perceptions regarding the stressor, and the perceived available resources to handle the stressor. Lazarus and Folkman (1984), conceptualize coping approaches by the individual's orientation to a problem, which can be either active or passive coping. Accordingly, individual's stress response includes either management or avoidance of the problem. The coping behaviors or methods are classified as problem oriented coping vs. cognitive/emotion regulation. Accordingly, the individual either engages in problem solving behaviors or tries to manage self-emotion towards the perceived stressor. Evidence shows that the coping approaches and coping behaviors frequently interact (see in Moos & Schaefer, 1993; Wills, 1997). Although coping with stress is a key component in the familial adjustment to the CHD (Thompson & Gustafson, 1996), no studies yet examined the early stress coping mechanisms of mothers of infants with complex CHD. The first objective of the current study is to qualitatively investigate how mothers of infants with complex CHD cope with stress during the pre- and post-operative period in the CICU. Learning about maternal coping is the first step in the process of tailoring stress-reduction interventions to this at-risk population. In the current study, Lazarus and Folkman's (1984) Stress and

Coping framework was used only in the final stages of data analysis, as a lens to understand the mothers' coping behaviors with stress.

Stress Reduction Interventions in CHD Populations

Thus far, parental interventions in CICU settings have generally been informative or educational, aiming to increase parental abilities to actively manage the caretaking demands of the CHD condition (Desai et al., 2002). For example, a skill development and empowerment intervention for PICU nurses, resulted in lower parental stress related to parental role alteration (Curley, 1988; Curley & Wallace, 1992). While the in-hospital support systems are widely available (Desai et al., 2002), no skill-building programs are available for mothers to help them proactively manage stress during the CICU stay, or after the transition to home. Despite recognition of the adverse effects of critical care on the familial well-being, interventions are currently needed aimed at improving parental coping behaviors with stress in critically ill pediatric settings. Stress management skills can empower parents to use proactive coping mechanisms in order to effectively advocate for their baby, improve their own physical and psychological well-being, and sustain a better quality of life for their families. Mindfulness has been used for a variety of patient populations both in hospital and community settings, and showed clinically significant long-term effects in reducing stress and treating anxiety and depression (Khoury et al., 2013).

Mindfulness

The mindfulness practice focuses on the acquisition of mindful awareness, through sustaining moment-to-moment perceptions of mental states and processes (i.e. physical sensations, affect, thoughts), eventually leading to their acceptance (Baer, 2003). Mindfulness strategies are diverse, but all have the common properties of refocusing attention on present sensations rather than cognitive rumination. Among the popular mindfulness techniques are 1) Mindful breathing: a focused attention on the breath cycle as a primary meditation object, while recognizing mind wandering; 2) Body-scan: systemically guiding attention through the different body parts, breathing into areas of tension; and 3) Compassion meditation: mentally rehearsing phrases of kindness, happiness, and empathy directed at oneself and others. Less familiar strategies include sitting meditation, walking meditation, mindful yoga, and more (see in Dimidjian & Linehan, 2009).

Mindfulness has been used in hospitals in the United States since the 1970s to treat stress-related medical and psychological conditions (Dimidjian & Linehan, 2009). Mindfulness interventions are currently used in a variety of clinical settings, ranging in length and in number of sessions (Baer, 2003). Research has shown that mindfulness is an effective way to reduce stress, regulate emotions, and even change the brain (Hölzel et al., 2013). Changes in attention, awareness, and emotion, have been observed throughout subjective, behavioral, and neurobiological assessments (Hölzel et al., 2013; Treadway & Lazar, 2009). Interventions show sustainable beneficial effects of mindfulness on stress, anxiety and depression, in healthy and ill populations (Khoury et al., 2013). For example, cancer patients reported on decreased stress and enhanced quality of life following mindfulness program, and in one year follow up. Consistently with their subjective reporting, patients' biologic indicators including immune, endocrine and blood pressure parameters, confirmed the post-intervention stress reduction (Carlson, Speca, Faris, & Patel, 2007). Despite mindfulness' beneficent effects on populations at-risk, such interventions have yet been disseminated in the CICU settings. While a pilot program showed decreased stress levels in PICU nurses (Gauthier, Meyer, Grefe & Gold, 2015), no such program has been tested on parents. The second objective of the current study was to explore mothers' perceptions regarding mindfulness, and their willingness to engage in such practice as a potential stress reduction intervention while their infant is admitted to the CICU, and after home

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