"Parenting a Child with a Chronic Health Condition: Examining Caregivers' Health Outcomes"

Courtney R. Lincoln

University of Connecticut Human Development and Family Studies

ABSTRACT

The prevalence of chronic health conditions (CHCs) in childhood is increasing, and more parents must learn to contend with the challenge of providing care to a child with a CHC (Cousino & Hazen, 2013; Klassen et al., 2007; Perrin et al., 2007; Pinquart, 2013; Van Cleave et al., 2010). Previous research indicates that parents of a child with a CHC experience high levels of caregiver burden and psychological distress along with high levels of perceived benefit as a result of parenting their child (Brandon, 2007; Chen & Newacheck, 2006; Guðmundsdóttir et al., 2006; Hatzmann et al., 2014; Hungerbuehler et al., 2011; Klassen et al., 2007; Nicholas & Keilty, 2007; Schneider et al., 2011). However, it is unknown how perceived benefit, caregiver burden, and psychological distress are concurrently related in parents of children with a range of ongoing health conditions. The current study used the Disability-Stress-Coping (DSC) model (Wallander & Varni, 1998) to examine caregivers' health outcomes for parents of children with a range of CHCs. Caregivers (N = 118) of a child with a CHC completed surveys assessing each of three risk and three protective factors outlined by the DSC model as well as study outcomes: perceived benefit, caregiver burden, and psychological distress. Results indicated that caregivers' perceived stress and emotion-focused coping were most strongly associated with all three health outcomes. The DSC model functioned well when assessing caregivers' negative health outcomes, but it needs revision to be effectively used as a tool to examine caregivers' perceived benefit. Study findings help inform strength-based interventionists seeking to bolster caregivers' strength and best support burdened and distressed caregivers.