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Changes in Family Functioning during the First Year of Pediatric Cancer Treatment: A Mixed-Method Pilot Study

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X Resident/Ph.D/post graduate (> 1 month of dedicated research time)

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IRB Number: STUDY00000678

Describe role of Submitting/Presenting Trainee in this project (limit 150 words):

Dr. Bates obtained internal funding for this work through a 2-year grant from the Children's Mercy Cancer Center Auxiliary. Dr. Bates is the PI of the project, conceived of the study, conducted and supervised data collection, mentored learners (Ms. Pallotto and Ms. Fornander) in data collection and data processing, ran analyses, and was the primary/lead author of the abstract and presentation.

Background, Objectives/Goal, Methods/Design, Results, Conclusions limited to 500 words

Background: A new diagnosis of pediatric cancer presents a sudden and tremendous stressor for families of all backgrounds and circumstances (Long & Marsland, 2011; Bemis et al., 2015). Although many families are resilient in the context of new cancer diagnosis, approximately 33% are at risk for negative outcomes due to psychosocial distress and difficulties with effective coping (Kazak et al., 2020; Pai et al., 2008), supporting the need for systematic assessment of psychosocial health as a standard of care in pediatric oncology (Kazak et al., 2015). Alongside heightened stress within the first year of diagnosis, parents may relax family rules and expectations for daily routines and in attempts to comfort and appease their suffering child (Crespo et al., 2013). However, family routines have been shown to promote positive adjustment and resiliency in the context of acute stress, including adjustment to illness (Harrist et al., 2019; Denny et al., 2012). Despite this, few studies have examined changes in family rules and routines in the context of new pediatric cancer diagnosis, or associations with demographics and caregiver functioning.

Objectives/Goal: The current study aimed to describe changes in family rules and routines during the first year of pediatric cancer treatment, and explore associations with demographic, illness factors, and caregiver distress.

Methods/Design: This is a mixed-methods, cross-sectional pilot study of 44 primary caregivers of youth who were in treatment for a new diagnosis of cancer in 2019 and 2020.

Caregivers completed validated questionnaires assessing demographic and child illness characteristics, psychosocial distress, and cancer-related stressors, and participated in a semi-structured interview discussing their family's rules and routines following new cancer diagnosis. Applied thematic analysis was utilized to extract key themes. Mixed method analyses included descriptive statistics and independent samples t-tests to examine variation in qualitative themes based on participant demographics and caregiver distress.

Results: Caregivers reported changes in many types of family rules and routines following new pediatric cancer diagnosis, including changes in bedtime (50%), mealtime (57%), and school routines (55%), relaxed behavioral expectations (27%) and changed screen time rules (43%). Caregivers also reported developing new routines following diagnosis to support infection control (52%), and treatment/medication demands (36%). Caregivers with elevated levels of psychosocial distress reported more changed rules and routines than caregivers with low levels of psychosocial distress ($t(42) = -2.50, p < .05$). Caregivers who endorsed more cancer-related stressors reported more new rules and routines than those who reported fewer cancer-related stressors ($t(42) = 2.07, p < .05$). Demographic and illness factors were not significantly associated with the number of changed, new, or stable family rules and routines ($p > .05$).

Conclusions: Changes in family functioning are common during the first year of pediatric cancer treatment. Psychosocial distress may be associated with more significant disruption to family practices. Caregivers may benefit from anticipatory guidance regarding normative disruptions to daily life during the first year of pediatric cancer treatment, and the potential benefits of consistent rules and routines to promote predictability and stability in the context of stress.