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

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Caregivers often relax family rules and routines during the first year of cancer treatment.

Qualitative interview themes (% families reporting theme):

**Changed mealtime or eating routines (57%)**:

- With him not having the best appetite, he just kind of eats whenever. Whatever he wants just to get something in him.
  - Mother of 6-year-old

**Relaxed screen time rules (43%) or behavior expectations (27%)**:

- As far as the phone and how much they play with their iPad things like that, that’s gone up a lot cause... I think I just let ‘em be happy, you know.
  - Father of 9-year-old

- I definitely think we’re more lax since she’s been diagnosed. I know they told me you know stick with it, keep the same discipline. But, it's hard when you feel bad.
  - Mother of 4-year-old

**Changed bedtime (50%) or school routines (54%)**:

- If he sleeps a lot during the day, then I don’t necessarily make him be in bed by 9:30.
  - Mother of 12-year-old

This study examined family rules and routines during the first year of cancer treatment, and associations with caregiver distress.

This study was funded by a Children’s Mercy Cancer Center Auxiliary Research Fund grant to Carolyn Bates, PhD.

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INTRODUCTION

- A new diagnosis of pediatric cancer is a major family stressor.
- Upholding consistent rules and routines may promote adjustment.
- However, numerous challenges may interfere with family practices during the first year of treatment.

This study examined family rules and routines during the first year of cancer treatment, and associations with caregiver distress.

METHOD

- Mixed-methods design
- Participants: N = 44 caregivers of children (age 18 mo-17 yrs) with new diagnosis of cancer within 1-year
- Measures:
  - Semi-structured interviews
  - Psychosocial Assessment Tool 2.0 (PAT2.0)
  - Response to Stress Questionnaire (RSQ)
- Analyses:
  - Interviews coded for key themes
  - Independent samples t-tests

RESULTS

- Caregivers with elevated psychosocial distress reported more changed rules/routines (t(42) = -2.50, p <.05).
- Caregivers who reported more cancer-specific stressors reported more new rules/routines (t(42) = 2.07, p <.05).

DISCUSSION

- A new diagnosis of pediatric cancer is a major family stressor.
- Upholding consistent rules and routines may promote adjustment.
- However, numerous challenges may interfere with family practices during the first year of treatment.

- The long-term impact of these changes warrants further study, because increases in lax parenting during cancer treatment have been associated with adverse short- and long-term child outcomes.
- Identifying protective factors from families who reported fewer changes in rules and routines may elucidate mechanisms of prevention.

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