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Recommended Citation

Bates CR, Pallotto IK, Moore RM, Covitz LM, Dreyer Gillette ML. Barriers and facilitators of family rules and routines during pediatric cancer treatment. *J Pediatr Nurs*. 2023;72:e33-e39. doi:10.1016/j.pedn.2023.06.002

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Barriers and facilitators of family rules and routines during pediatric cancer treatment

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ARTICLE INFO

Article history:

Received 23 January 2023

Revised 31 May 2023

Accepted 1 June 2023

Keywords:

cancer
Oncology
Pediatrics
Family
Psychosocial

ABSTRACT

Objective: Pediatric nurses work closely with families of children with new cancer diagnoses and can provide essential supports to promote coping and adjustment. This cross-sectional qualitative study aimed to gather caregiver perspectives on barriers and facilitators to adaptive family functioning during the early phases of cancer treatment, with a focus on family rules and routines.

Methods: Caregivers ($N = 44$) of a child diagnosed with cancer and receiving active treatment completed a semi-structured interview about their engagement in family rules and routines. Time since diagnosis was abstracted from the medical record. A multi-pass inductive coding strategy was utilized to extract themes identifying caregiver-reported facilitators and barriers to maintaining consistent family rules and routines during the first year of pediatric treatment.

Results: Caregivers identified three primary contexts that presented barriers and facilitators to engagement in family rules and routines: the hospital setting ($n = 40$), the family system ($n = 36$), and the broader social and community setting ($n = 26$). Caregivers reported barriers primarily related to the demands of their child's treatment, additional caregiving needs, and needing to prioritize basic daily tasks (e.g., food, rest, household needs). Caregivers reported that different networks of support across contexts facilitated family rules and routines by expanding caregiver capacity in distinctive ways.

Conclusions: Findings provided insight into the importance of having multiple networks of support to extend caregiving capacity in the context of cancer treatment demands.

Practice implications: Providing nurses with training to facilitate problem-solving skills in the context of competing demands may provide a new avenue of clinical intervention at the bedside.

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Families learning of a new diagnosis of pediatric cancer are thrust into a period of stress and uncertainty. While many families are resilient during a new diagnosis of pediatric cancer, a subset experience challenges with coping and adjustment that increase risk for negative psychological outcomes for children, caregivers, and siblings (Katz et al., 2018; Van Warmerdam et al., 2020). Pediatric nurses are at the forefront of working with families with new cancer diagnoses, and often provide point-of-care support and guidance to promote adaptive family functioning and adjustment to illness (Kearney, Salley, & Muriel, 2015; Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). However, the complex

and intense nature of the early stages of pediatric cancer treatment may present challenges to implementing anticipatory guidance and nursing recommendations (Drotar, 2005; Hocking et al., 2014; Stehl et al., 2009). Gathering caregiver perspectives on barriers and facilitators to adaptive family functioning during the early phases of cancer treatment may support ongoing intervention adaptation and improve nursing care delivery.

A component of cognitive behavioral and family systems intervention frameworks, structured family rules and routines play an important role in child and adolescent development. Through engagement in predictable daily practices, family routines enhance the parent-child relationship and promote the development of youth's executive functioning skills (Fiese et al., 2002; Ackerman & Brown, 2010). Some daily routines, such as family mealtimes, may also contain ritualistic

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components that hold symbolic meaning (e.g., saying grace, having special foods for certain occasions), which further promote family cohesion (Spagnola & Fiese, 2007). Predictable limits, such as limitations around child screen time, promote a sense of predictability and security and support the development of child self-regulation skills (Houck & Lecuyer-Maus, 2004). Engagement in these behaviors promotes positive development from early infancy through adolescence (Barton et al., 2019; Spagnola & Fiese, 2007). Beyond the day-to-day benefits for child development, upholding consistent family routines and rules during periods of acute stress has been shown to exert a protective influence on psychological functioning for children and families by maintaining elements of predictability, stability, and parent-child bonding within uncertain circumstances (Harrist, Henry, Liu, & Morris, 2019; Santos, Crespo, Canavarro, Alderfer, & Kazak, 2016). Conversely, reducing engagement in previously established rules and routines during periods of high stress, such as a new cancer diagnosis, may exacerbate a sense of unpredictability and increase risk for poor adjustment across the family system (Neugebauer & Mastergeorge, 2021). Studies suggest that family rules, routines, and rituals are associated with adaptive functioning, quality of life, and family cohesion and hope during pediatric cancer treatment (Bates et al., 2021; Santos et al., 2016). Although many stressors of childhood cancer diagnosis and treatment cannot be altered, family rules and routines are modifiable behaviors that may improve families' abilities to cope and adapt to a new cancer diagnosis and mitigate psychological sequelae (Santos et al., 2016; Sloper, 2000).

Despite potential benefits of engaging in family rules and routines during periods of stress, a large body of literature demonstrates that new pediatric cancer diagnosis disrupts family functioning (Pai et al., 2007). In a qualitative study of ten Flemish families of a child with Leukemia or lymphoma, parents reported changes in family cohesion, adjusted approaches to child-rearing/parenting, and loss of normalcy in family life while striving to maintain normalcy in small ways (Van Schoors et al., 2018). Individual factors, such as the child's disease and treatment characteristics (Christensen & Carlsen, 2022) and parent appraisal of the illness (Van Schoors et al., 2019) may influence how family functioning changes in the context of a new cancer diagnosis. Fewer studies have examined specific changes in family rules and routines, though the literature suggests that caregivers tend to adopt more lax approaches to parenting during the earlier stages of treatment (Williams & McCarthy, 2015; Williams et al., 2014). In a recent qualitative study, caregivers endorsed changes in their family's mealtime and eating routines (57%), children's bedtime routines (50%), and rules around screen time during pediatric cancer treatment (43%; Bates et al., 2021). However, families also reported maintaining consistency across some behaviors, even during the early stages of treatment (e.g., 45% reported stable bedtime routines, 39% reported stable mealtime/eating routines), or creating new routines to accomplish novel tasks such as medication administration (36%; Bates et al., 2021). Notably, families who reported higher levels of psychosocial distress also reported more disruption to their family rules and routines (Bates et al., 2021).

As pediatric nurses frequently provide in-the-moment support to families during the intensive early phases of cancer treatment (Kazak et al., 2007; Kazak, Schneider, Didonato, & Pai, 2015), a deeper understanding of impacting factors that limit or promote engagement in potentially protective family behaviors may enhance the delivery of point-of-care nursing support. Specifically, identifying modifiable barriers may highlight contributing sources of stress that could be mitigated through effective intervention. Additionally, identifying modifiable factors that may facilitate engagement in these positive behaviors would elucidate mechanisms of intervention. The current study aimed to explore barriers and facilitators to engagement in family rules and routines during the first year of pediatric cancer treatment, to inform clinical work with this population, and inform intervention development. Results are intended to be hypothesis generating in order to inform intervention adaptations and new lines of clinically focused research in this population.

Method

Data for this cross-sectional, qualitative study are part of a larger mixed-methods study examining caregiver-reported changes in family functioning during the first year of a new cancer diagnosis (Bates et al., 2021). The current study presents data reporting on barriers and facilitators to family rules and routines, which has not been published elsewhere. Data were collected from October 2019–March 2020 in a large children's hospital in the Midwestern United States. Recruitment for the larger study was paused for four months following the onset of the COVID-19 pandemic. Due to the confounding impact of COVID-19 lockdown on family functioning, as well as having an adequate pre-pandemic sample size to achieve thematic saturation (Hennink & Kaiser, 2022), the current study presents only data collected prior to the pandemic.

All study procedures and informed consent processes were approved by the hospital's Institutional Review Board. Families of a child that received a new cancer diagnosis within the past year were identified using an institutional clinical research database. Families were screened for eligibility using the institutional electronic medical record; inclusion criteria for caregivers included being the primary caregiver and legal guardian of a child who was 1) diagnosed with cancer in the last year, 2) between 18 months–17 years, and 3) undergoing active treatment (e.g., chemotherapy, radiation, bone marrow transplant). Families were deemed ineligible if 1) the child was undergoing treatment for a recurrence or secondary malignancy, or 2) caregivers were non-English speaking. Study personnel approached caregivers of eligible patients during outpatient oncology clinic appointments. Participating caregivers provided written informed consent and participated in a semi-structured interview with trained study staff.

Semi-Structured Interview. A 12-item semi-structured interview was developed as part of the larger study to examine changes in family functioning following a new diagnosis of cancer (Bates et al., 2021). The interview generally asked families to describe their household rules and routines prior to their child's cancer diagnoses and the ways in which these behaviors did or did not change following their child's cancer diagnosis. Questions were created based on a literature review, including ecological systems theory (Bronfenbrenner, 1986) and the family stress model (Masarik & Conger, 2017). Ecological systems theory presents how the child is at the center of concurrent and intersecting subsystems such as the family system and hospital system (Bronfenbrenner, 1986). The family stress model demonstrates how child problems can stem from economic pressure causing parental distress (Masarik & Conger, 2017). The full semi-structured interview is published elsewhere (Bates et al., 2021). The current analysis focuses on caregiver responses to the following questions: 1) "What helped you keep these rules or routines? How have you managed?" and 2) "What are the barriers to keeping up with the family rules and routines you might like to be sticking with?" though caregiver discussions of barriers or facilitators at any point during the interview were reviewed for inclusion in analyses. Interviews lasted 13 min, 1 s on average ($SD = 5$ min, 8 s) and were conducted by a trained post-baccalaureate research assistant and a psychology resident/intern.

Analytic Plan. All interviews were de-identified, transcribed, and checked for accuracy by trained data transcriptionists. Interviews were imported into Dedoose software, version 8.0.25 for data management and analysis. Data coding and analysis were conducted by lead authors, CRB and IKP, with additional input from senior author MDG. A multi-pass, content analysis approach was utilized, guided by Saldaña (2009) structured coding framework. Topical codes were developed a priori based on the interview guide. These codes include family rules, family routines, barriers, and facilitators. Family rules were coded when caregivers discussed any specific or enforced requirements for behavior such as limits for screen time or rules for speaking kindly. Family routines were coded when caregivers referenced family practices with two or more actors that occurred commonly, such as bedtime or

mealtimes. Anything that caregivers cited as preventing family rules and/or routines or making them difficult to maintain was coded as a barrier, and anything that caregivers felt supported family rules and/or routines was coded as a facilitator. Codebook is available upon request.

In the initial stage of analysis, coders read through in initial five interviews and extracted key themes to create an initial coding framework of sub-topical emergent codes. Examples of sub-topical emergent codes include “infection control” practices as a type of routine and “inpatient admissions” as a kind of barrier (Table 2). Coders independently utilized this framework to double code the participant interview with the most utterances, and adequate interrater reliability was achieved ($\kappa = 0.86$). A primary coder, IKP, then coded the remaining transcripts using the existing coding framework. Any novel or unclear excerpts were discussed with CRB and MDG, and resolved through negotiated agreement. Novel emergent codes were created through team discussion and iteratively incorporated into the existing framework, including recoding prior interviews. We did achieve thematic saturation prior to the completion of coding as there were no new conceptual insights outside of the existing coding scheme for the final interviews. The current analysis focused on codes and themes that identified barriers and facilitators to family rules and routines.

Results

Approximately 92% of caregivers who were approached for the study agreed to participate. Demographic information for caregivers ($n = 44$) and children is presented in Table 1. Caregivers described barriers and facilitators to family rules and routines during the first year of pediatric cancer treatment across three broad contexts: the family system, hospital setting, and broader social and community supports. Table 2 lists emergent themes with example quotes from participants across each context and category and suggestions for intervention.

Family system

Caregivers identified barriers and facilitators within the family system that impacted their ability to engaged in family rules and routines. Non-modifiable barriers included feeling that there is “not enough time in the day” (20%, $n = 9$) and limited emotional bandwidth (16%, $n = 7$)

Table 1
Demographic characteristics.

N = 44	Frequency (%)	M (SD)
Caregiver demographics		
% Biological parents	98	
% Female	79	
% Married	71	
% College educated	47	
Child demographics		
Age (years)		7.54 (4.86)
% Female	52	
% White	78	
% Non-Hispanic	91	
Cancer diagnosis		
Leukemia	43	
Solid tumor	34	
Lymphoma	12	
Brain tumor	11	
Months since diagnosis		5.09 (3.07)
Health insurance		
Private	55	
Medicaid	36	
Self-pay or uninsured	9	
Family demographics		
People living in home (n)		4.41 (1.34)
Adults (n)		1.86 (0.66)
Children (n)		2.45 (1.15)

to manage cancer caregiving needs and other basic needs of daily life. Moreover, caregivers described that at times, previously established rules and routines (e.g., family mealtimes, limiting screen time) were incompatible with other necessary tasks, such as demands of treatment (e.g., medication administration, getting through clinic appointments), and simply not having the capacity to “do it all” at the same time.

Many caregivers cited family support (66%, $n = 29$), including help from a partner or extended family members, as potentially modifiable facilitators of consistent family rules and routines when the primary caregiver was unavailable or occupied with cancer caregiving tasks. Modifiable facilitators are factors over which the family has control that make upholding rules and routines more manageable. Family support may be a modifiable facilitator if caregivers are able to ask grandparents, extended family members, or siblings to assist in maintaining normal family functioning. Parents cited family members as potential substitute caregivers if and when these individuals had pre-existing familiarity with typical family routines: “we also have [my husband’s] mom that helps take care of the kids. So that helps stabilize with everything and that she knows all of our routines” and “we’ve had so much support to kind of fill in where one of us has to be absent to take care of my daughter and her treatment. We’ve had so many people that we know very well and trust completely to help maintain those rules and routines.” Moreover, families discussed upholding bedtime and mealtime routines with siblings and other family members even when the primary caregiver or ill child was not able to participate. Siblings facilitated routines through continued engagement in school/activity routines, but caregivers also reported that siblings could present barriers to new routines (e.g., around treatment needs or infection control practices) if they were resistant to routine changes to accommodate the ill child.

Hospital setting

Caregivers described elements of the hospital setting, including clinic visits, inpatient admissions, and interaction with primary oncology team, as either facilitators (50%, $n = 22$) or barriers (41%, $n = 18$) to family rules and routines. Inpatient admissions were described as a non-modifiable barrier that completely removed the ill child and caregiver from their homes and other daily activities. Broader demands of the child’s treatment regimen, including medication schedules, clinic visits, and isolation precautions ($n = 6$), were also noted as non-modifiable barriers to preexisting family routines, as these new rules and routines often superseded preestablished family practices (e.g., siblings’ routines, family outings). One parent commented on limited family outings following their child’s diagnosis, “One of the difficult things is really you can’t leave [the house]. We’re afraid to go outside and being far from the hospital, so I feel like that limits what we do with our older child too.” Another parent mentioned having to relax routines with older siblings to focus on the sick child, “[When] we’re having to do a lot of chemo...we were stressed trying to...we don’t have time to read [siblings] a story. We were trying to get her medicine.”

Clinical providers and psychosocial supports were often cited as modifiable facilitators of family rules and routines (50%, $n = 22$). Social workers connected families with resources and practical assistance, such as access to transportation, lodging, and financial assistance, which relieved family stress around basic needs so caregivers could focus on parenting. Medical teams, including oncologists, nurse practitioners, and bedside nurses, supported family adjustment to the new diagnosis and provided anticipatory guidance around managing treatment and potential side effects. One parent reported, “the nurses are wonderful here and they answer questions and take care of us like we’re family here.” Caregivers reported that receiving information about their child’s diagnosis and treatment plan facilitated family routines by allowing caregivers to plan family activities around the child’s medical needs.

Table 2

Frequency of participants endorsing facilitators and barriers to family rules and routines, exemplar quotes, and clinical interventions to consider. Participant-reported facilitators and barriers are organized in accordance with Ecological Systems Theory (Bronfenbrenner, 1986).

Themes	n*	Total Codes	Example quote	Interventions to consider
Facilitators	44	188		
Support from other family members	29	47	"...my mom lives in town and so she's been able to help out a lot."	
Hospital support	22	35	"I've been really happy, extremely happy and lucky to have this hospital 'cause I feel like our doctor and the nurses do a really good job of explaining why we're doing this and how we're doing that." "The camaraderie between parents has been really the most beneficial."	<ul style="list-style-type: none"> • Development or referral to parent-to-parent programs • Hospital-based support groups (e.g., in person or virtual) • Facilitate other opportunities for families to interact (e.g., in common spaces) • Connect to social workers • Connect with financial assistance services
Friends/peer support	19	25	"For us definitely we've had a lot of supports from our friends, we have a lot of friends, she has a good friend base."	<ul style="list-style-type: none"> • Introduce parents to appropriate social media (such as CaringBridge, Courageous Parents Network) • Create a list of peer supports that caregivers can call on in moments of need
Communication	15	23	"Just talking to her dad like we are not together, we co-parent and which can make it even harder going back and forth. So we just make sure to communicate like hey this is going on here. This is how she's been and this is what I expect, how do you feel about that?"	<ul style="list-style-type: none"> • Support parents in writing down or maintaining ongoing list of questions • Consider problem solving skills training (e.g., Bright Ideas; Sahler et al., 2005)
Little things	16	21	"People to turn to just to you know take care of like our dogs when we're here...just the little things you don't think about"	<ul style="list-style-type: none"> • Consider patient, family, or teen advisory councils • Create and disseminate list of small but significant supports (e.g. grocery shopping, cleaning house) that friends or family can contribute
Parent employment	15	16	"We've been fairly fortunate with work. They've kind of allowed me to take time off when he's been in chemo."	<ul style="list-style-type: none"> • Connect with social workers to review policies (e.g., FMLA)
Faith	11	14	"...because we believe in God. We believe that He's going to help us through this"	<ul style="list-style-type: none"> • Connect families with chaplaincy or explore supports within their existing faith community
Community	7	9	"we have had a lot of support ... with the people in our county ... They've done all kinds of fundraisers and you know have just been really, really helpful"	<ul style="list-style-type: none"> • Connect caregivers to local and/or national charitable organizations and support programs • Consider additional social service resources (Variety, 2023)
Child cooperation	4	7	"She's pretty good at taking her medicine. She's a good girl. She doesn't fight me. She knows, she gets it"	<ul style="list-style-type: none"> • Utilize Child Life services • Connect with pediatric psychologist • Utilize pediatric Psychology Resource Bank (Carter, 2022) • Utilize swallowing resources (Kaplan et al., 2016)
Barriers	38	93		
Inpatient/clinic	18	22	"One of the biggest ones was when it's- like when he had to be hospitalized for a while...one of the parents [was not there] and the other parent [was] worried"	<ul style="list-style-type: none"> • Advocate for flexible scheduling to meet family needs when possible • Check in on parents meeting basic needs (e.g., eating, sleeping, resting) • Coordinate volunteer services to give parents "breaks" • Coordinate or encourage use of Ronald McDonald House resources
Financial	13	14	"Money is always going to be a problem because no matter what, bills don't stop"	<ul style="list-style-type: none"> • Check in on basic needs (e.g., food, clothing, utilities, equipment) • Connect caregivers to financial assistance resources (Variety, 2023) • Connect caregivers to social workers when needed
Infection control	6	11	"We definitely take it to consideration all of his labs before we're attending anything...especially during the cold and flu season like with other children around."	<ul style="list-style-type: none"> • Support and empower families to practice infection control outside of the hospital • Refer families to infection control specialists to discuss specific guidelines (e.g., masking, sanitizing practices)
Siblings	7	9	"It's been difficult... having another child with similar age I think it helps you keep that benchmark...if you do something for our youngest and you can't do it for [younger child] and she doesn't understand, she'll become jealous and she doesn't see the big picture of what's going on."	<ul style="list-style-type: none"> • Encourage opportunities for sibling involvement, education, and connection to treatment process (Gerhardt, Lehmann, Long, & Alderfer, 2015) • Connect siblings to child life specialists or pediatric psychologist if higher level of support is needed (Alex's Lemonade Stand, 2023; HopeKids, 2023; Sibling Support Project, 2023)
Time	9	9	"Those routines are kind of hard to keep up with honestly each day, 'cause you just run out of time you know."	<ul style="list-style-type: none"> • On inpatient unit, work with family to implement daily schedule (e.g., for vitals, medicines, cares)
Transportation	7	9	"...the thing that was the hardest for all of us that I mentioned before is the traveling."	<ul style="list-style-type: none"> • Connect caregivers to Ronald McDonald House resources • Help caregivers navigate insurance (e.g. Medicaid transportation) and/or hospital-based options (e.g., shuttles)
Parent capacity	4	7	"...just sometimes I don't have energy for the fight...and if there was you know one more thing I got to take on under the day, it's just not you know what I had a long day at work, we've been in appointments or whatever that is, and that I'll get to it later."	<ul style="list-style-type: none"> • Connect with social work or financial services for gas gift cards • Consider problem-solving skills training (e.g., Bright Ideas; Sahler et al., 2005) to prioritize needs and create action plan • Provide information on accessing mental health support or treatment (Caregiver Wellbeing SIG, 2022)
Patient challenges	5	6	"We're trying to get her medicine. We can't- she's fighting us because it's a steroid, it taste bad, and we got to figure out a way [give it] to her a little bit at a time so she still gets it."	<ul style="list-style-type: none"> • Consider problem-solving skills training (Bright Ideas; Sahler et al., 2005) to help parent create action plan to address specific challenges • Connect with Child Life at bedside • Connect with pediatric psychologist
Caregiver distress	4	4	"I just get discouraged and it's just difficult sometimes to keep up with the little things and that should be included."	<ul style="list-style-type: none"> • Consider problem-solving skills training (Bright Ideas; Sahler et al., 2005) • Refer to hospital-based mental health supports (e.g., pediatric psychology, family therapy)
Parent employment	1	2	"My husband wasn't able to work for almost two and half months just because our son was so sick"	<ul style="list-style-type: none"> • Connect with social worker

* n indicates the number of unique caregivers in the sample who endorsed each theme.

Social support

Caregivers endorsed various sources of community support including friends (43%, $n = 19$), community members (16%, $n = 7$), and faith organizations (20%, $n = 9$) that provided practical support and emotional respite. Caregivers' workplaces were described as having the potential to be either a facilitator (34%, $n = 15$) or barrier (5%, $n = 2$) to maintaining consistent family routines, depending on their employer's flexibility and level of support. Though caregivers discussed great appreciation of support from non-familial friends, caregivers did not typically see their friends as direct facilitators of rules and routines (i.e., not able to step in as surrogate caregivers). Instead, instances where caregivers' larger communities provided acts of service (36%, $n = 16$) such as raising money, bringing meals or groceries, or hiring a house cleaner indirectly facilitated rules and routines by relieving some basic responsibilities, allowing caregivers to focus on cancer caregiving and other higher-order family functioning.

Interactions between systems. The aforementioned systems of support do not exist in isolation. Caregivers reported success maintaining rules and routines when interactions between different support systems occurred. For example, caregivers reported leaning on faith practices and communities to provide financial aid, physical support (e.g., meals) and routines and rituals for family. Several caregivers reported that religion allowed their family to have a shared routine (e.g., one parent reported, "Religion is religion and just staying together as a family, doing things together.") Caregivers underscored the importance of connecting with other families in the hospital's pediatric cancer unit because of the unique support they could lend. One parent reported, "I think other families [are] great because they can talk to you not like the doctors talk to you. They can talk to you like a regular person in layman's term... sometimes it's good to like hear their, maybe see their kids who have beat it... if their kid could do it, my kid could do it." Individual factors, like parent capacity, suggested that certain parents needed more support from factors in the ecological microsystem (e.g., family) and exosystem (e.g., hospital) than others (e.g., one parent reported, "as a single parent I'm very stressed from my job. I work a lot of hours in executive position that I do not handle stress nearly as well as I should"). Additionally, caregivers' macrosystem (e.g., faith) broadly influences the ways that clinicians can provide support.

Discussion

The purpose of this study was to identify and describe barriers and facilitators to consistent engagement in family rules and routines during the first year of pediatric cancer treatment to better understand factors that may limit or promote engagement in potentially protective behaviors during this period of high stress. Results suggest that a childhood cancer diagnosis directly and indirectly interfered with families' capacity to engage in rules and routines across various contexts. Despite these barriers, caregivers reported some facilitators across settings that supported their ability to maintain family rules and routines during their child's cancer treatment. Takeaways from this study can inform point-of-care nursing with families of children with cancer.

Across settings, caregivers reported barriers to maintaining family rules and routines that centered around the demands of treatment and meeting basic daily needs. Challenges balancing tasks of cancer caregiving with other responsibilities, such as managing work and finances, care for siblings, and other basic household demands left caregivers with fewer mental, physical, and emotional resources to implement structured rules and routines in the home, which is consistent with the Family Stress Model (Masarik & Conger, 2017; Neugebauer & Mastergeorge, 2021). Descriptions of essential medical and basic family needs taking priority over family routines suggests that caregivers were frequently faced with prioritizing tasks based on a hierarchy of needs (Maslow & Lewis, 1987), spending most of their time meeting the family's basic physiological and safety needs

(e.g., food, medication, and financial security) with limited personal capacity for higher levels of psychological or self-fulfillment needs. Family routines may be particularly challenging to implement during the early phases of treatment, when families are still adjusting to the diagnosis and treatment is often most intense (Crespo et al., 2013). Moreover barriers, such as financial strain (Warner, Kirchhoff, Nam, & Fluchel, 2015) and sibling needs (Long et al., 2018), created more demands on families' basic needs, and caregivers described that with limited social support these needs fell on caregivers alone. Importantly, this sample was comprised of mainly White, non-Hispanic, married, and biological caregivers, so results likely do not capture the full range of barriers that families may experience during the first year of cancer treatment. Future work should explore additional barriers to family functioning that may be experienced by families with diverse racial, ethnic, and socioeconomic characteristics.

Despite numerous barriers, caregivers reported several facilitators in the hospital, family, and community settings that expanded their capacity to meet their family's basic needs and to promote engagement in family rules and routines. One of the main novel findings in this study is that caregivers reported minimal overlap in the support they received between different settings, suggesting that supports within each context played a unique role in supporting the needs of family life. This is not surprising, as the positive impact of adequate social support for families during early phases of cancer treatment is well-established (Patenaude & Kupst, 2005) and benefits both caregiver and child coping with treatment (Davidson et al., 2023; Harper et al., 2019). Among families with fewer resources and/or higher levels of caregiver anxiety or depression (Harper et al., 2016), size of social support network is a significant predictor of caregiver and family adjustment to new cancer diagnosis. Indeed, results from this study illuminate a potential pathway by which sources of social support across the family, hospital, and community contexts may collectively offset the increased burden of cancer treatment to help families meet their basic needs in addition to assisting with cancer caregiving. Connecting families with psychosocial resources that can assess pre-existing family vulnerabilities (e.g., financial and caregiving resources) and size and satisfaction with current social supports may be an important first step to identifying modifiable needs in this area.

Guidance from care providers on maintaining family rules and routines appeared to empower caregivers to stick with their preestablished rules and routines even when they may want to adjust to cater more to their sick child (Thompson & Young-Saleme, 2015). However, from a clinical perspective, results suggest that, though helpful, anticipatory guidance and education around rules and routines may not be sufficient to enable individual caregivers to carry out recommended behavioral family practices when they are facing numerous co-existing physiological and safety needs. Nurses should be aware of competing demands that family may face even when attempting to manage family tasks in the context of cancer treatment, and that additional supports are essential to facilitate higher-level family practices (Landier et al., 2016).

Limitations

This study has several limitations that should be noted to appropriately contextualize our findings. First, this is an exploratory study using a small sample of caregivers from a single institution. Thus, results are not exhaustive but rather are intended to be hypothesis-generating. As mentioned above, our sample contains limited racial, ethnic, and sociodemographic diversity. Systemic racism continues to limit representation of historically underrepresented groups in clinical research. Future work using culturally tailored recruitment and retention strategies (e.g., partnering with community groups, including participants with limited English proficiency) may capture cultural variations in family functioning and/or the specific needs of children and families with marginalized identities (Valrie, Thurston, & Santos, 2020). Caregivers in our sample were relatively highly educated, thus it is also

possible that findings do not generalize to samples with lower levels of caregiver education. Finally, we did not have access to information regarding the type or amount of psychosocial support that caregivers or youth received during their cancer treatment, although there is a strong presence of psychologists and social workers at our institution. Level of psychosocial support could certainly impact family engagement in positive coping strategies, and certainly merits consideration in future, large scale studies.

Implications for practice

When working with families who are struggling to engage in consistent family behavioral practices due to being overwhelmed by other needs, it may be useful to examine their contexts of support and explore ways to increase connectedness or “share the load” with others who are willing to help (Doupnik et al., 2017). Caregivers may also benefit from practical assistance around organizing and utilizing available resources. Problem-solving skills training (PSST; Sahler et al., 2005) protocols may be beneficial to help families identify their highest priority needs and/or barriers and teaching practical skills, including utilization of resources, to address those needs, thereby enhancing perceptions of personal control. Importantly, PSST has also been shown to reduce levels of caregiver distress following new pediatric cancer diagnosis (Dolgin et al., 2021; Sahler et al., 2005), which may further support engagement in family rules and routines (Bates et al., 2021). While nurses are capable of learning and delivering PSST (Voll et al., 2022), these protocols have not been widely disseminated within pediatric oncology nursing. Focusing on PSST training with nurses, who frequently work with families at the bedside, could fill a significant gap and provide new avenues of intervention with families who are struggling to implement practical treatment recommendations.

Conclusions

This study provides insight into the barriers to adaptive functioning that families may face during the first year of pediatric cancer treatment, as well as facilitating supports that may help families to overcome these barriers to engage in behavioral treatment recommendations, specifically engaging in consistent rules and routines. Clinicians should aid families in identifying barriers to engaging consistent rules and routines, determining which barriers are modifiable, and then make suggestions on how to overcome these non-systemic barriers. Findings provided particular insight into the importance of social support networks to extend caregiving capacity in the context of treatment demands. These findings reinforce the use of Bronfenbrenner's Ecological Systems Theory to conceptualize factors influencing the functioning of children with cancer. Consistent with the psychosocial standards of care (Kearney et al., 2015), helping families identify and connect with available networks of support during pediatric cancer treatment may be key to promoting adaptive family functioning by engaging in consistent family rules and routines. Training nurses, who are often the front-line treatment team members, in empirically supported problem-solving skills training interventions may be a worthwhile future direction in clinical research to support caregivers to overcome barriers and utilize available supports to promote adaptive family adjustment to treatment (Dolgin et al., 2021).

Availability of data and material

Data supporting these findings are available from the first author by reasonable request.

Code availability

N/A.

Ethics approval

All study procedures were approved by the Children's Mercy Kansas City's Institutional Review Board.

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Consent for publication

All authors provide consent for publication of this work.

Acknowledgements/funding

The project was funded by the Children's Mercy Cancer Center Auxiliary.

CRediT authorship contribution statement

Carolyn R. Bates: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – original draft, Supervision, Project administration, Funding acquisition. **Isabella K. Pallotto:** Methodology, Formal analysis, Writing – original draft, Visualization. **Rachel M. Moore:** Supervision, Resources, Writing – review & editing. **Lynne M. Covitz:** Supervision, Resources, Writing – review & editing. **Meredith L. Dreyer Gillette:** Conceptualization, Methodology, Data curation, Resources, Supervision, Project administration, Funding acquisition.

Declaration of Competing Interest

None.

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