Article

Not peer-reviewed version

Risk and Resilient Functioning of Families of Children with Cancer during the COVID-19 Pandemic

Renee Gilbert , Carolyn Bates * , Devanshi Khetawat , Meredith L Dreyer Gillette , Rachel Moore

Posted Date: 31 January 2023

doi: 10.20944/preprints202301.0568.v1

Keywords: cancer; pediatrics; psycho-oncology; family; COVID-19; risk; resilience

Article

Risk and Resilient Functioning of Families of Children with Cancer during the COVID-19 Pandemic

Renee Gilbert [1], Carolyn Bates [2,3,*], Devanshi Khetawat [1], Meredith L. Dreyer Gillette [2] and Rachel Moore [2]

[1] University of Kansas—Clinical Child Psychology Program, Dole Human Development Center, Lawrence, KS, 66044
[2] Children's Mercy Kansas City—(1) Department of Pediatrics, University of Kansas Medical Center, Kansas City KS, 64114;
[3] University of Kansas Cancer Center, Kansas City, KS 64114
* Correspondence: cbates4@kumc.edu; 2000 W Olathe Blvd, Mailstop 4004, Kansas City, KS 66160

Abstract: Previous literature highlights the impact of COVID-19 on family functioning. Less is known about the impact of the pandemic on families of pediatric cancer patients. In order to determine universal and unique risk and resilience factors of these families during the pandemic, a qualitative analysis was conducted on families currently receiving cancer treatment at a midwestern hospital. Results of the data analysis depict ways in which these families have been impacted by and have adapted to COVID-19. These findings suggest that families of pediatric cancer patients have unique experiences in the context of COVID-19, in addition to universal experiences outlined in previous literature.

Keywords: cancer; pediatrics; psycho-oncology; family; COVID-19; risk; resilience

1. Introduction

The COVID-19 pandemic presents several unprecedented challenges for children and adolescents [1]. Specifically, it has had significant ramifications for families of youth with chronic pediatric health conditions. Global health and economic uncertainty alongside state and local stay-at-home orders during the COVID-19 pandemic resulted in substantial changes to daily life [2]. For instance, the pandemic led to several alterations in the family home environment and organization [3]. These significant changes could increase susceptibility to psychosocial risk, as well as open opportunities for resilience among families with children and adolescents [4]. Of note, families of children undergoing cancer treatment may have experienced unique challenges and stressors during the COVID-19 pandemic as children undergoing chemotherapy were at high-risk for COVID-19 infection [5–7]. Given the importance of family functioning on child and caregiver psychological outcomes during pediatric cancer treatment [8], and the direct role of the family during the COVID-19 pandemic [4], it is important to understand the unique experiences of families of children with cancer during the COVID-19 pandemic to promote long-term psychosocial wellbeing among children with cancer and their families throughout public health crises.

Extant research advances mixed outcomes when exploring the psychosocial outcomes of COVID-19 among families of pediatric cancer patients. On the one hand, some studies suggest that the social disruptions that emerged in the wake of COVID-19 may have a negative impact on family functioning and routines [4]. Changes in daily activities and familial roles that accompany childhood cancer can also function as added stressors [9]. Thus, given the increased susceptibility to COVID-19 among youth with cancer, heightened disruptions to resources and support, and increased financial demand, negative psychosocial outcomes can be anticipated [10–12]. An Italian study found that caregivers reported clinically significant levels of posttraumatic stress, acute stress, and anxiety during the pandemic [13]. A British study found that caregivers no longer viewed the hospital as a "safe place" and generally endorsed feeling highly worried about the pandemic and vigilant [14]. Caregivers in an American study reported disruptions in anxiety, sleep, eating habits, mood, exercise, stress, and financial status [15]. Hence, globally, the COVID-19 pandemic has been associated with negative psychosocial outcomes for families with children and adolescents with cancer.

Despite these findings, resilience has also been demonstrated in families of children and adolescents with cancer during the COVID-19 pandemic. Prior to the COVID-19 pandemic, families generally display resilience in the face of a cancer diagnosis and treatment [16,17]. Emerging literature, however, suggests that these families may be uniquely resilient in the face of the COVID-19 pandemic. A Dutch study found reduced levels of caregiver distress following the advent of the pandemic [18]. Another study in the U.S. found that caregivers generally reported adjusting well to the pandemic [19]. One reason for these positive findings may be that families of pediatric cancer patients are "uniquely prepared" for the COVID-19 pandemic. Indeed, families may have taken precautions prior to the pandemic (e.g., masking, social distancing) that mimic COVID-related measures [19]. Additionally, decreased social and job demands, increased family time, access to education technology and healthcare may lead to a reduction of stress in these families [20]. Processes like meaning making, flexibility, connectedness, social and economic resources, and collaborative problem solving may foster familial resilience [21]. Previous work has found that greater family cohesion, expressiveness and support were associated with better psychosocial outcomes for both pediatric patients and their siblings [17]. While certain findings currently demonstrate evidence of increased challenges for these families, there is also evidence of resilience and adaptive adjustment in the face of COVID-19. Thus, an in-depth exploratory study is needed to investigate the presence of risk and resilience in these families.

Prime and colleagues [4] developed a conceptual framework derived from literature on family systems theory [22,23], Bronfenbrenner and Morris' bioecological model [24], a family stress model [25] and developmental systems theory [24]. Authors suggest a cascading influence of the COVID-19 pandemic on child adjustment, in which social disruptions lead to heightened distress among caregivers, impacting dyadic relationships within the family (marital, parent-child, siblings). This may in turn impact family processes that influence child adjustment. This model is a "mutually reinforcing system", in which stress in one domain may lead to stress in another [4]. Within this framework, pre-existing vulnerabilities (e.g., economic hardship, racism and marginalization) may serve as risk factors for families, increasing vulnerability to social disruptions and other COVID-19 related complications, whereas family well-being (e.g., good communication, organization and strong belief systems) may increase resilience or serve as a protective factor against these disruptions [4]. Prime and colleagues have identified familial processes and individual factors that may increase risk or promote resilience during the COVID-19 pandemic; however, less is known about whether or not this theoretical framework aligns with families of pediatric cancer patients. Findings of the present study will identify unique risk and protective factors to best inform clinicians who work with these families.

Purpose of the Current Study

This qualitative study aims to describe the psychosocial risk and resilience among families of children who were receiving active cancer treatment during the onset of the COVID-19 pandemic. Guided by the theoretical framework proposed by Prime et al., we aim to understand experiences of families that are consistent with the general impact of the pandemic on families across the US (regardless of child cancer diagnosis), and highlight unique impacts of the pandemic on families of children with cancer. In order to support and promote well-being in families of pediatric cancer patients throughout the COVID-19 pandemic and during future public safety hazards, it is important to identify areas of resilience and potential areas of vulnerability.

2. Materials and Methods

This study is part of a larger study that began prior to the COVID-19 pandemic that sought to examine changes in the family home environment following a new diagnosis of pediatric cancer [28].

A subset of study data was collected during the COVID-19 pandemic, and these data were examined separately from the larger dataset given the impact of the COVID-19 pandemic on the family home environment. Families were recruited from a large children's hospital in the Midwestern U.S. Primary caregivers of children who met the following eligibility criteria were identified via the institution's clinical research database: 1) between the age of 18 months – 17 years, 11 months, 2) diagnosed with cancer within the past year, 3) living within the home of a legal guardian and not in foster care, and 4) undergoing active treatment (i.e., chemotherapy, radiation, or bone marrow transplantation). Participants were deemed ineligible if their child was diagnosed with a recurrence or secondary malignancy. Primary caregivers also needed to be English speaking to complete semi-structured interviews. With primary medical team approval, participants were approached by study personnel during outpatient oncology clinic appointments, or remotely via phone, to conduct informed consent and administer study measures. The hospital's Institutional Review Board approved all study procedures. The authors report there are no competing interests to declare.

A total of 31 parents (24 mothers and 7 fathers) participated in the qualitative portion of the main study. The mean age of children was 6.6 years old (SD= 4.21) and ranged between 18 months to 16 years. Females made up 50% of the sample of children. The sample was primarily white (78%). Families had an average of 4.90 people living in the home (SD = 1.46) with a range of 3-9 individuals. Fifty-six percent of the sample had a diagnosis of leukemia, and average time since diagnosis was 9.18 months with a range of 1.50 – 20.83 months. Table 1 displays the demographic characteristics of the sample.

The data presented in the current analysis were collected after the onset of the COVID-19 pandemic between July 2020 and January 2021. The current sample is a subset of participating families who completed COVID-19 measures during the first year of the pandemic.

Table 1. Demographic Characteristics of Participating Caregivers (N=31) and their Children Receiving Cancer Treatment.

Demographics	*M (SD)*	Percentile (%)
Caregiver		
Female sex		78
Marital Status		
Single		13
Married/Partnered		78
No response		9
Education Level (%)		
Finished high school or GED		3
Started college or trade school		22
Finished college or trade school		41
Finished masters or doctorate		16
No response		9
Child		
Age (years)	6.61 (4.21)	
Female sex		50
Race		
White/Caucasian		78
Black/African American		6
Hawaiian / Other Pacific Islander		6
Multi-Racial		3

No response		7
Non-Hispanic Ethnicity		91
Insurance Type		
Private		71
Medicaid		19
Government, COBRA, or Self-pay		10
Diagnosis		
Leukemia		56
Solid Tumor		16
Lymphoma		16
Brain/CNS Tumor		6
Other		6
Time since Diagnosis (months)	9.18 (6.48)	
Number of people living in home	4.90 (1.46)	

Measures

Qualitative Assessment

Prior to the COVID-19 pandemic, a 12-item semi-structured interview was created to examine differences in family functioning and the home environment following a new diagnosis of cancer [28]. These initial questions were developed from a review of literature consisting of models of family functioning in response to stress, including the Family Stress Model and Ecological Systems Theory. Families responded to open-ended questions regarding family rules and routines before the diagnosis, and changes or lack thereof following the diagnosis. Following the onset of the COVID-19 pandemic, additional questions were added where caregivers were asked to specify changes that occurred for the family since the pandemic. These questions were added to capture the supplemental impacts of the pandemic on family routines following a new pediatric cancer diagnosis.

Analytic Plan

Directed Content Qualitative Analysis

All semi-structured audio recordings were de-identified, transcribed, and double checked for accuracy by trained data transcriptionists. Interviews then were imported into Dedoose software, version 8.0.25 for data management and analysis. Data coding and analysis were conducted by authors RG and DK with oversight by CRB and additional input from senior author RM. Authors utilized directed content analysis to examine pre-determined themes derived from Prime and colleagues' model of risk and resilience of family well-being during the COVID-19 pandemic [4]. This model proposes that the COVID-19 pandemic influenced children's adjustment via influences of social disruptions, caregiver well-being and pre-existing vulnerabilities. This study sought to explore family functioning following a cancer diagnosis during the COVID-19 pandemic, using the PRIME Model to develop pre-determined themes. Coders (RG, DK) utilized this framework to independently code each interview separately, compared codes, and resolved discrepancies through negotiated agreement with additional input from CRB and RM [see 26,27].

3. Results

Throughout the interviews, parents discussed the impacts of pediatric cancer and COVID-19 and ways of adapting. Several categories emerged, including organization, social disruptions, pre-existing vulnerabilities, communication, belief systems and psychological and physical well-being. Within each category, various themes surfaced that depicted the experiences of these families.

Organization

Family organizational processes, including rules, routines, and rituals, were disrupted by both the child's cancer diagnosis and the COVID-19 pandemic. Families discussed that treatment-related tasks (e.g., clinic appointments, medication administration) and infection control measures (e.g., social distancing, handwashing) became the top priority for the family as a whole. Thus, other rules, routines, or rituals that conflicted were often adjusted or relaxed. For example, screen time limitations were often relaxed for the ill child, as the phone or iPad was used as a tool to promote entertainment and compliance at clinic appointments. Many families implemented new rules or routines around cleanliness and infection control to protect their immunocompromised child even prior to COVID-19 pandemic, and discussed re-engaging these strategies during the onset of the pandemic:

> *"I said something like having the kids at first, we were very strict about them coming home and changing clothes and even family members, making sure they were washing hands and stuff as soon as they walk in doors and stuff like that. Once she progressed on through her treatment, we got a little more relaxed on some of that. Course now, COVID happened some of that stuff has picked back up and we're a lot stricter on things again."* (Father of 3-year-old)

Families acknowledged challenges around social distancing and infection control limiting their contact with extended family and friends, although ways of creatively staying in touch (e.g., connecting through social media; socially distanced meal delivery) were also discussed. Given infection control restrictions, families discussed appreciation for continued access to their hospital's social worker to provide practical resources.

Families also discussed several positive adaptations in the face of these disruptions, including savoring increased togetherness through rituals such as eating meals together when everyone in the family was at home, which promoted family bonding. Parents expressed gratitude for additional caregivers working from home and able to provide back-up childcare for siblings when needed (e.g., when one parent was needed at the hospital). Families discussed increased access to classroom and school material through the provision of universal online schooling, though also acknowledged the challenges of completing schoolwork on days when their child was not feeling well in the context of many other demands.

Social Disruptions

Families report many social disruptions during this time. While they expressed that COVID-19 itself led to increased isolation and cancellation, families expressed that several aspects of the cancer diagnosis interfered with social functioning. These included things like extensive hospital stays, increased susceptibility to illnesses and impairing illness-related symptoms (e.g., fatigue). Families reported that both COVID-19 and the cancer diagnosis caused disruptions in engagement in extracurriculars and physical activities (including sports), routine family outings, employment, church, school, and social interactions. Families frequently noted a shift to online formats for school, church and even family gatherings (via televideo). Some families expressed that COVID-19 caused increase social isolation, above and beyond the cancer diagnosis:

> *"Well, personally, we attended church until now. But I think it was more social distance than her diagnosis because we were still going to church and everything."* (Mother of 16-year-old)

Families report various consequences of these social disruptions. Families expressed that school closures and cancer treatment increased screen time and decreased structured schedules. Families also reported concerns for increased behavioral difficulties and socially inappropriate behaviors due to isolation. They reported a lack of family time at dinner, and limited spousal support. They also reported financial strains due to loss of work. Families expressed decreased support from extended family members that they typically relied on. They reported that extensive hospital stays had a negative impact on the cancer patient, due to isolation from family members:

> *"[She's] having to stay in the hospital for 5 days when she was diagnosed and just the amount of mental health stress that put on her, not being near her brothers and sisters."* (Mother of 7-year-old)

Some families also reported minimal or positive impacts of these social disruptions. Some reported that there had been little-to-no disruptions in their family routine. Some families reported that the isolation has increased family time at home. They also reported that a shift to work-from-home has given parents increased availability for cancer treatment obligations. Some families noted that the children were happy to not go to school. Families reported appreciation for the COVID-19 pandemic:

> *"I hate to say it, but the coronavirus probably has helped us get through a lot of that a lot of this as a family because unfortunately it caused us to all be home... there's just a lot of things we didn't have to worry about 'cause we're just stuck at home anyway you know. My husband hasn't been to work, he just works from home now... I think it would've looked a lot different if it weren't for coronavirus because he would've been going to work, my other child would've been going to school participating in activities. So, the coronavirus has probably helped support our future because it's given us all you know a reason that we were all at home together through it all."* (Mother of 9-year-old)

Pre-existing vulnerabilities

Families reported that several psychosocial, familial, and environmental vulnerabilities which pre-dated the cancer diagnosis served as barriers to treatment in the COVID-19 context. Living away from the treatment location was a specific inconvenience as families indicated that they found it difficult to develop the support network for immediate emotional, relational, and physical support. For instance, families reported not knowing enough resources or parent groups with a child having a cancer diagnosis:

> *"So that's been our biggest challenge is finding all the support that we need when we're not in Kansas City cause when we're Kansas City it's much easier. Like there's Ronald McDonald, like there's parents' parents, there's places who'll buy toys for the kids if they are bored, there's all this stuff but now that we're not in Kansas City and we're home there's not any of that. so, finding that outright support has been difficult."* (Mother of 3-year-old)

Many families also suggested that having complex family dynamics and multiple children at home can be challenging as parents must balance out the needs of all children, and not just the one who has cancer. Complex parenting plans can add challenges as the rules and organizational structures varies across homes. This makes it difficult to maintain consistency of care and expectations. Families further indicated that finances could function as a barrier, wherein some families were grateful for having insurance, and others expressed gratitude for having one stay-at-home parent to manage treatment and daily activities. Additionally, environmental constraints, such as cleanliness and living standards can cause additional concerns:

> *"Well right after... [he] was diagnosed, we had the home tested for mold 'cause you can't live in an environment where there is mold... Our home tested positive for mold. So, they started tearing things out to see where things were at, and it was everywhere. So right after he was diagnosed, we couldn't go home."* (Mother of 3-year-old)

Communication

For families of pediatric cancer patients, communication was not only important within families, but with their medical teams as well. Varied communication patterns were noted within families, and among families and their medical teams and the larger communities. From their medical teams, families reported that receiving concrete information, through visuals, videos, and verbally about scans, X-Rays, the mechanism of cancer, and the treatment plan, helped families feel involved in the process and stay away from the vague and often incorrect information propagated online. Further, families often engaged with medical professionals about how to promote their children's resilience and positive adaptation to the diagnosis. Participants reported that doctors encouraged families to maintain consistency, allow their children to complete their daily chores, and minimize any cancer-related alterations to their daily functioning:

> *"They even warned us like don't let her do whatever she wants. Don't spoil her and we're like oh yeah for sure and then we did just because it's so hard to watch 'em go through all that so, but it ended up backfiring I feel like."* (Mother of 6-year-old)

For these families, communication within families and to extended networks of family and friends was also important during this time. Within families, participants report having multiple conversations with the child's siblings about how there is not special treatment for the child with cancer, and instead the child's cancer can warrant some changes in rules. Participants indicated that they reiterate the importance of staying away from germs to all family members, including siblings and visitors. This includes not going outside without masks, not touching surfaces unnecessarily, sanitising everything including hands, not hugging strangers, and taking showers and washing hands constantly. Importantly, families reported that these messages were not only to minimize germs for the child's cancer, but also to minimize the spread of COVID-19. Thus, they reported that COVID-19 made it easier for them to explain the germ policies to strangers, siblings, and other family members. Other families indicated that they often communicated the germ policies after COVID-19, similar to the changes they had to incorporate at the beginning of cancer treatment.

Belief Systems

Family belief systems were evident as they discussed child-rearing, responsibilities, family cohesion and faith. Families appeared to adapt some of their belief systems to the present circumstances. Families' belief systems also helped to foster resilience in the face of COVID-19 and cancer. Cancer and the pandemic may have challenged previous beliefs and values about parenting. In order to adjust, parents discussed being more lenient in their expectations for their children:

> *"…probably we let a lot more of the little things fly. Don't get on her as much for small things. You know if she wets her pants or knocks stuff over you know we just try to let little things fly that aren't going to matter you know in 5 hours from now."* (Mother of 4-year-old)

Parents did, however, also rely on previous beliefs and expectations for their children throughout cancer treatment. Families discussed the importance of keeping age-appropriate expectations for behavior now so that the child will be well-behaved later. Families also discussed beliefs about family time and normality as top priorities. Some families reported that COVID-19 had some benefits for their family in terms of increased time together. Others discussed the importance of keeping normalcy in the household throughout cancer treatment:

> *"... we needed to keep some sense of normalcy. You know there's- I knew there's things in my house that I can control and cancer I can't control."* (Mother of 3-year-old)

> *"…we're trying to stay as close to normal, to normalcy as possible. But we're trying to, for everybody at home to have as close to a normal life as possible."* (Mother of 2-year-old)

Families also relied on values of faith and family strength to endure cancer and related challenges:

> *"Teaching her how to be a warrior like I was doing that before we got cancer so when we know we got cancer now we're [about] to beat this too. It's just a culture in our house that we're strong, we're*

> *faithful, we accomplish things, we conquer, and I think that would be something that I would teach someone else that maybe doesn't have that or hadn't been doing it for their kid."* (Mother of 7-year-old).

Psychological and Physical Well-being

Families reported psychological and physical impacts due to COVID-19 and cancer diagnoses. Families discussed numerous impacts of cancer and its treatment on their children's physical well-being, including fatigue, low energy, physical limitations, and intense procedures. Families also noted increased vulnerability to illnesses, like the flu and COVID-19, due to being immunocompromised. Families discussed increased accommodations for the child due to cancer and treatment. Families often noted being lenient with rules and expectations:

> *"...we are definitely a lot more relaxed I think in the rules. We don't probably enforce them as much as we did beforehand, I think probably just the guilt kind of that comes along with that since she's already going through so much."* (Mother of 4-year-old)

Parents reported negative impacts on their mental health as well. They discussed increased anxiety, stress, and guilt due to cancer. They also reported the impact of COVID-19 on getting the social support they need:

> *"Right now, what has made it harder is like for example my husband and I do everything together. And now we're having to split because of COVID and that has been very hard for me to go through this without him here."* (Mother of 2-year-old)

Families also discussed the distress they've felt as a whole:

> *"...you just feel like you're just constantly trying to get your head above water, catch your breath and figure something out and then you get pushed back under. So, it's like we're trying to understand what he has going on and what his cancer means and what our life is going to mean."* (Mother of 3-year-old)

Some families report access to resources to address some of their mental health needs. These resources include individual therapy, couples therapy and Facebook groups. However, many families report a need for additional resources:

> *"...there's no, there's no one to talk to about it. There's like- besides going in and seeing a therapist- there's not really a lot where you can be like this is really challenging as a parent..."* (Mother of 3-year-old)

Families report that overtime, stress did decrease:

> *"I'd say now that um we're not as stressed because now that he entered his maintenance phase of treatment, and he seems to be doing- like- he acts normal and seems to be doing normal... I do feel like honestly other than when we go to the hospital and stuff everything seems just kind of normal to me... I wouldn't say there's a lot of high stress related to his diagnosis anymore."* (Mother of 9-year-old)

4. Discussion

The present study sought to investigate risk and resilience factors among families of pediatric cancer patients during the COVID-19 pandemic. The study was guided by the theoretical framework developed by Prime and colleagues to understand universal and unique impacts of the pandemic on these families. Findings suggest that COVID-19 has impacted families in several areas, and additional risk and resilience factors during this time exist in pediatric cancer populations.

doi:10.20944/preprints202301.0568.v1

In accordance with Prime and colleagues' theoretical framework, families in the present study reported distress due to COVID-related social disruptions. Families report that COVID-19 led to several social disruptions, including school closures, job loss, decrease in extracurricular activities, decrease in support and resources, and isolation from extended family and friends. Families reported experiencing distress due to lack of social support and mental health resources. These findings align with the Prime framework [4], in which they suggest that social disruptions may negatively impact caregiver well-being, family processes and child adjustment. Indeed, previous work suggests that increased COVID-19 disruptions to daily life is associated with higher levels of psychosocial distress [3].

These disruptions, though, have important implications and consequences for families of pediatric cancer patients. Caregivers report increased psychological distress due to their children's cancer diagnosis and treatment, including increased anger, anxiety, depression and posttraumatic stress symptoms [29]. Further, families in the present study reported COVID-related disruptions in social support and mental health resources, which may be crucial to mitigate this psychological distress. Indeed, increased perceived social support may have positive implications for well-being in caregivers of children with cancer, whereas a perceived lack of social support may lead to increased psychological impairment [30,31]. In addition, psychological interventions for caregivers and siblings of children with cancer may have important psychological benefits [32,33]. Thus, a lack of social support and mental health resources due to the pandemic, as reported by these families, may have negative implications.

Pediatric cancer patients may experience limitations to their autonomy and mobility during intense therapy [34]. COVID-19 restrictions are an additional barrier for children and families to sports and other physical activities. Yet physical activity may have mental health benefits for children with or without cancer, including increased self-esteem [35,36]. Additionally, specific benefits of physical activity for pediatric cancer patients include increased quality of life, sleep efficiency and decreased fatigue [37,38].

Prime and colleagues also theorized that pre-existing vulnerabilities (e.g., economic difficulties, health conditions, trauma history, racism and marginalization) would amplify consequences of the pandemic for families [4]. In our sample, a pediatric cancer diagnosis itself may represent a pre-existing vulnerability. Indeed, for some families, the cancer diagnosis led to social isolation, school dismissal and limited physical activity prior to COVID-19. Additionally, parents reported cancer-related disruptions including lengthy hospital stays and demanding treatment.

The COVID-19 pandemic has led to a general increase in mental health difficulties, with a 25% increase in depression and anxiety [39]. However, parents in the present study have reported cancer-related mental health issues, including increased parental guilt, stress, worry and anxiety regarding the diagnosis, which supports previous work [29]. Additionally, parents in the present study report children experiencing cancer-related physical and psychological concerns, including increased stress, fatigue, lack of energy, sleep concerns, worsening mood, and behavioral difficulties. The COVID-19 pandemic may exacerbate prior mental health issues, especially for these families [40].

Parents reported additional pre-existing vulnerabilities, including socioeconomic status, location, and race. Sociodemographic factors may place a subset of families with a pediatric cancer patient at risk for increased levels of distress [41]. Families reported various difficulties due to their geographic location, including a lack of resources and long distance from the treatment center. Previous literature suggests that geographic areas may have implications for cancer-related health outcomes; in fact, Carriere and colleagues [42] suggest that rurality leads to lower survival rates of cancer, potentially due to lower engagement in treatment and screening. Additionally, moving to a new location for treatment may lead to social stress. For example, families of color reported worries about racism during this time. Racism may have negative mental health consequences and physical health consequences [43]. However, further investigation is warranted to evaluate how race-related stress may impact outcomes of pediatric cancer patients and families.

Pediatric cancer also places a financial burden on families, due to expensive treatment, caregiver medical leave, travel and lodging costs and other nonmedical expenses [44]. For some families already at a socioeconomic disadvantage (e.g., low-income, single-parent household), a cancer diagnosis and treatment may exacerbate these concerns [41]. Further, pediatric cancer-induced financial burden may worsen parental distress already experienced due to the cancer diagnosis [45]. Job loss and financial strain due to COVID-19 may increase financial difficulties for these families.

Families in the present study adapted to COVID-19 and cancer through systems of organization and communication. Previous work emphasizes the importance of consistent family rules and routines during times of stress, including after a cancer diagnosis [28] and during the COVID-19 pandemic [3]. However, families in the present study reported many cancer and COVID-related disruptions to rules and routines. Indeed, families reported ridding of set schedules for their children, relaxing previous rules set (e.g., bedtime), increased screen time and decreased family time (e.g., family dinner). Parental accommodation and laxness are associated with emotional, behavioral and sleep difficulties in children with cancer [46,47].

Families, however, also reported the development of new rules and routines to adapt to the COVID-19 pandemic and the cancer diagnosis. In their model, Prime and colleagues emphasize *organization* (i.e., access to resources, connectedness, and adaptability) as an important family process that might be disrupted, or act as a source of resilience, during the COVID-19 pandemic [4]. Many families in the present study reportedly engaged in and prioritized routines regarding cleanliness and infection control, including social distancing, isolation and sanitization practices and some families reported feeling uniquely prepared for the pandemic, given they already engage in these practices. Families also discussed ways in which they adapted to COVID-19 disruptions, through alternating or changing schedules and reliance on additional family members.

Prime and colleagues also note the importance of communication within families during the pandemic, described as “clear information, emotional sharing, collaborative problem-solving, dyadic and family coping” [4]. This theory is consistent with the present study, as families in the present study emphasized the importance of communicating with other family members regarding safety protocols for cleanliness and infection control. Caregivers also reported needing to communicate to the patient’s siblings regarding expectations about rules and routines, and clarification about the patient receiving what siblings perceive as “special treatment”. Previous literature with families of pediatric cancer patients emphasizes the importance of open and clear communication with healthy siblings: open communication may serve as a successful coping strategy [48–52]; closed communication may lead to jealousy, resentment, and feelings of being left out [50].

For families in the present study, however, communication was also an important process for relationships with the medical team. Indeed, caregivers reported feelings of gratitude when they received clear, concrete information from their providers about the diagnosis, treatment, and suggestions for parenting strategies. Families also reported dissatisfaction with the way information about cancer was relayed to them, noting that certain explanations were difficult to understand and not family friendly. Empathic communication is crucial when discussing information with families of pediatric cancer patients, due to significant levels of stress and anxiety caregivers may experience during this time [53,54].

Limitations

This study has several limitations to acknowledge. First, the hospital at which this study was conducted serves a population that is predominantly White and non-Hispanic, along with the sample in the present study. This limits our ability to capture cultural differences in family functioning in the context of COVID-19 and cancer, which may have important implications for treatment. Barriers exist that limit recruitment and engagement of marginalized communities in research studies, and it is important that these barriers are addressed in future work [55]. Additionally, caregivers in our study were highly educated and married, and thus our findings may not adequately capture families with less education and single-parent households. Given that our data capture the impact of the pandemic only at one specific time point (i.e., first year of the pandemic), more work is needed to understand the short- and long-term, impact of the pandemic on families of children receiving cancer treatment.

Clinical Implications

Results of the present study have crucial clinical implications for families of pediatric cancer patients during the COVID-19 pandemic. The Prime model [4] emphasized the importance of mental health interventions for families during this time, citing universal psychosocial consequences that may result from the disruptions of the pandemic. Our present study, however, has implications for the unique, long-term needs of these families who endured the first year of the COVID-19 pandemic during their cancer treatment, and for the short-term needs of future families of children receiving cancer treatment during times of increased health concerns (e.g., flu or RSV seasons). Families of children receiving treatment during the first year of the COVID-19 pandemic may require ongoing screening and mental health treatment given the multiple stressors they endured during this time. As they transition out of treatment and into survivorship care, it is crucial that they receive adequate support. Future families of pediatric cancer patients during times of public health crises may benefit from accessible, virtual mental health services available on short notice, in addition to continued assessment of family needs during unpredictable times.

5. Conclusions

The current qualitative study sought to evaluate risk and resilience factors of families of pediatric cancer patients throughout the COVID-19 pandemic. Guided by Prime and colleagues' theoretical framework, our findings suggest that these families have some experiences that aligned with the universal impacts of COVID-19 on families, but also have unique experiences. Results suggest that families of pediatric cancer patients may already experience mental health challenges, including general distress and anxiety, and that COVID-19 may have intensified those symptoms. These families also experienced financial burden due to cancer-related costs, and COVID-19 lead to additional burden. COVID-19 may lead to disruption in rules and routines, and the up-keep of these expectations is crucial for child adjustment in these particular families. These families may have strength during this time, as they may have been uniquely prepared for COVID-19 mandates, including handwashing and social distancing. Clear communication is a universal resilience factor for families during the pandemic and during cancer treatment. Families of the present study emphasize the importance not only of communication between family members, but with the medical team as well. Interventions aimed at promoting resilience of families of pediatric cancer patients during the pandemic should be sure to address the unique needs of these families at this time.

Author Contributions: For research articles with several authors, a short paragraph specifying their individual contributions must be provided. Conceptualization, C.B., M.D.G.; methodology, C. B., M. D. G.; formal analysis, R.G., C.B., D.K., R.M..; writing—original draft preparation, R.G., C.B. ; writing—review and editing, R.G., C.B., D.K., M. D. G; funding acquisition, C. B., M. D. G. All authors have read and agreed to the published version of the manuscript.

Funding: This study is supported by funding from the Children's Mercy Cancer Center Auxiliary Research Fund to Carolyn Bates, PhD.

Institutional Review Board Statement: Study procedures and consent were approved by the Children's Mercy Kansas City Institutional Review Board (IRB#STUDY0000678).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study

Data Availability Statement: The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Acknowledgments: The authors would like to thank Alexandra Hartwig for her assistance with data collection. We would also like to thank our study participants for sharing their experiences.

Conflicts of Interest: The authors declare no conflict of interest.

References

1. Lee, J. Mental Health Effects of School Closures during COVID-19. *Lancet Child Adolesc. Health* **2020**, *4* (6), 421. https://doi.org/10.1016/S2352-4642(20)30109-7.
2. NBCNews.com. *Stay at home orders across the country.* https://www.nbcnews.com/health/health-news/here-are-stay-home-orders-across-country-n1168736. (accessed 2023-01-09).
3. Bates, C. R.; Nicholson, L. M.; Rea, E. M.; Hagy, H. A.; Bohnert, A. M. Life Interrupted: Family Routines Buffer Stress during the COVID-19 Pandemic. J. Child Fam. Stud. 2021, 30 (11), 2641–2651. https://doi.org/10.1007/s10826-021-02063-6.
4. Prime, H.; Wade, M.; Browne, D. T. Risk and Resilience in Family Well-Being during the COVID-19 Pandemic. Am. Psychol. 2020, 75 (5), 631–643. https://doi.org/10.1037/amp0000660.
5. ElGohary, G. M.; Hashmi, S.; Styczynski, J.; Kharfan-Dabaja, M. A.; Alblooshi, R. M.; de la Cámara, R.; Mohmed, S.; Alshaibani, A.; Cesaro, S.; Abd El-Aziz, N.; Almaghrabi, R.; Gergis, U.; Majhail, N. S.; El-Gohary, Y.; Chemaly, R. F.; Aljurf, M.; El Fakih, R. The Risk and Prognosis of COVID-19 Infection in Cancer Patients: A Systematic Review and Meta-Analysis. Hematol. Oncol. Stem Cell Ther. 2022, 15 (2), 45–53. https://doi.org/10.1016/j.hemonc.2020.07.005.
6. Liang, W.; Guan, W.; Chen, R.; Wang, W.; Li, J.; Xu, K.; Li, C.; Ai, Q.; Lu, W.; Liang, H.; Li, S.; He, J. Cancer Patients in SARS-CoV-2 Infection: A Nationwide Analysis in China. Lancet Oncol. 2020, 21 (3), 335–337. https://doi.org/10.1016/S1470-2045(20)30096-6.
7. Tan, J.; Yang, C. Prevention and Control Strategies for the Diagnosis and Treatment of Cancer Patients during the COVID-19 Pandemic. Br. J. Cancer 2020, 123 (1), 5–6. https://doi.org/10.1038/s41416-020-0854-2.
8. Katz, L. F.; Fladeboe, K.; King, K.; Gurtovenko, K.; Kawamura, J.; Friedman, D.; Compas, B.; Gruhn, M.; Breiger, D.; Lengua, L.; Lavi, I.; Stettler, N. Trajectories of Child and Caregiver Psychological Adjustment in Families of Children with Cancer. Health Psychol. 2018, 37 (8), 725–735. https://doi.org/10.1037/hea0000619.
9. Van Schoors, M.; De Mol, J.; Morren, H.; Verhofstadt, L. L.; Goubert, L.; Van Parys, H. Parents' Perspectives of Changes within the Family Functioning after a Pediatric Cancer Diagnosis: A Multi Family Member Interview Analysis. Qual. Health Res. 2018, 28 (8), 1229–1241. https://doi.org/10.1177/1049732317753587.
10. Clerici, C. A.; Massimino, M.; Ferrari, A. On the Clinical Psychologist's Role in the Time of COVID-19, with Particular Reference to Experience Gained in Pediatric Oncology. Psychooncology 2020, 29 (9), 1374–1376. https://doi.org/10.1002/pon.5418.
11. Seth, R.; Das, G.; Kaur, K.; Mohanaraj, R.; Siri, P.; Wajid, M. A.; Mandal, P.; Sahoo, D.; Thomas, T.; Raina, M.; Gupta, A. K.; Meena, J. P. Delivering Pediatric Oncology Services during a COVID-19 Pandemic in India. Pediatr. Blood Cancer 2020, 67 (12), e28519. https://doi.org/10.1002/pbc.28519.
12. Wimberly, C. E.; Towry, L.; Caudill, C.; Johnston, E. E.; Walsh, K. M. Impacts of COVID-19 on Caregivers of Childhood Cancer Survivors. Pediatr. Blood Cancer 2021, 68 (4), e28943. https://doi.org/10.1002/pbc.28943.
13. Guido, A.; Marconi, E.; Peruzzi, L.; Dinapoli, N.; Tamburrini, G.; Attinà, G.; Balducci, M.; Valentini, V.; Ruggiero, A.; Chieffo, D. P. R. Psychological Impact of COVID-19 on Parents of Pediatric Cancer Patients. Front. Psychol. 2021, 12, 730341. https://doi.org/10.3389/fpsyg.2021.730341.
14. Darlington, A.-S. E.; Morgan, J. E.; Wagland, R.; Sodergren, S. C.; Culliford, D.; Gamble, A.; Phillips, B. COVID-19 and Children with Cancer: Parents' Experiences, Anxieties and Support Needs. Pediatr. Blood Cancer 2021, 68 (2), e28790. https://doi.org/10.1002/pbc.28790.
15. Fisher, A. P.; Patronick, J.; Gerhardt, C. A.; Radonovich, K.; Salloum, R.; Wade, S. L. Impact of COVID-19 on Adolescent and Emerging Adult Brain Tumor Survivors and Their Parents. Pediatr. Blood Cancer 2021, 68 (9), e29116. https://doi.org/10.1002/pbc.29116.
16. Van Schoors, M.; Caes, L.; Verhofstadt, L. L.; Goubert, L.; Alderfer, M. A. Systematic Review: Family Resilience after Pediatric Cancer Diagnosis. J. Pediatr. Psychol. 2015, 40 (9), 856–868. https://doi.org/10.1093/jpepsy/jsv055.
17. Van Schoors, M.; Caes, L.; Knoble, N. B.; Goubert, L.; Verhofstadt, L. L.; Alderfer, M. A. Systematic Review: Associations between Family Functioning and Child Adjustment after Pediatric Cancer Diagnosis: A Meta-Analysis. J. Pediatr. Psychol. 2016, jsw070. https://doi.org/10.1093/jpepsy/jsw070.
18. van Gorp, M.; Maurice-Stam, H.; Teunissen, L. C.; van de Peppel-van der Meer, W.; Huussen, M.; Schouten-van Meeteren, A. Y. N.; Grootenhuis, M. A. No Increase in Psychosocial Stress of Dutch Children with

Cancer and Their Caregivers during the First Months of the COVID-19 Pandemic. Pediatr. Blood Cancer 2021, 68 (2), e28827. https://doi.org/10.1002/pbc.28827.

19. Chardon, M. L.; Klages, K. L.; Joffe, N. E.; Pai, A. L. H. Family Adjustment to Pediatric Hematopoietic Stem Cell Transplant during COVID-19. J. Pediatr. Psychol. 2021, 46 (10), 1172–1181. https://doi.org/10.1093/jpepsy/jsab092.
20. Serlachius, A.; Badawy, S. M.; Thabrew, H. Psychosocial Challenges and Opportunities for Youth with Chronic Health Conditions during the COVID-19 Pandemic. JMIR Pediatr. Parent. 2020, 3 (2), e23057. https://doi.org/10.2196/23057.
21. Walsh, F. Family Resilience: A Framework for Clinical Practice. Fam. Process 2003, 42 (1), 1–18. https://doi.org/10.1111/j.1545-5300.2003.00001.x.
22. Carr, A. The Evolution of Systems Theory. In Handbook of family therapy; Routledge, 2015; pp 13–29.
23. APA Handbook of Contemporary Family Psychology: Foundations, Methods, and Contemporary Issues across the Lifespan (Vol. 1); Fiese, B. H., Celano, M., Deater-Deckard, K., Jouriles, E. N., Whisman, M. A., Eds.; American Psychological Association: Washington, 2019.
24. Handbook of Child Psychology, Volume 1, Theoretical Models of Human Development, 6th ed.; Damon, W., Lerner, R. M., Eds.; John Wiley & Sons, 2006.
25. Conger, R. D.; Conger, K. J. Resilience in Midwestern Families: Selected Findings from the First Decade of a Prospective, Longitudinal Study. J. Marriage Fam. 2002, 64 (2), 361–373. https://doi.org/10.1111/j.1741-3737.2002.00361.x.
26. Watts, F. M.; Finkenstaedt-Quinn, S. A. The Current State of Methods for Establishing Reliability in Qualitative Chemistry Education Research Articles. Chem. Educ. Res. Pr. 2021, 22 (3), 565–578. https://doi.org/10.1039/d1rp00007a.
27. O'Connor, C.; Joffe, H. Intercoder Reliability in Qualitative Research: Debates and Practical Guidelines. Int. J. Qual. Methods 2020, 19, 160940691989922. https://doi.org/10.1177/1609406919899220.
28. Bates, C. R.; Pallotto, I. K.; Moore, R. M.; Fornander, M. J.; Covitz, L. M.; Dreyer Gillette, M. L. Family Rules, Routines, and Caregiver Distress during the First Year of Pediatric Cancer Treatment. Psychooncology 2021, 30 (9), 1590–1599. https://doi.org/10.1002/pon.5736.
29. Sloper, P. Predictors of Distress in Parents of Children with Cancer: A Prospective Study. *J. Pediatr. Psychol.* **2000**, *25* (2), 79–91. https://doi.org/10.1093/jpepsy/25.2.79.
30. Manne, S.; DuHamel, K.; Redd, W. H. Association of Psychological Vulnerability Factors to Post-Traumatic Stress Symptomatology in Mothers of Pediatric Cancer Survivors. *Psychooncology* **2000**, *9* (5), 372–384. https://doi.org/10.1002/1099-1611(200009/10)9:5<372::aid-pon471>3.0.co;2-1.
31. Marsland, A. L.; Long, K. A.; Howe, C.; Thompson, A. L.; Tersak, J.; Ewing, L. J. A Pilot Trial of a Stress Management Intervention for Primary Caregivers of Children Newly Diagnosed with Cancer: Preliminary Evidence That Perceived Social Support Moderates the Psychosocial Benefit of Intervention. *J. Pediatr. Psychol.* **2013**, *38* (4), 449–461. https://doi.org/10.1093/jpepsy/jss173.
32. Salem, H.; Kazak, A. E.; Andersen, E. W.; Belmonte, F.; Johansen, C.; Schmiegelow, K.; Winther, J. F.; Wehner, P. S.; Hasle, H.; Rosthøj, S.; Bidstrup, P. E. Home-Based Cognitive Behavioural Therapy for Families of Young Children with Cancer (FAMOS): A Nationwide Randomised Controlled Trial. *Pediatr. Blood Cancer* **2021**, *68* (3), e28853. https://doi.org/10.1002/pbc.28853.
33. Prchal, A.; Landolt, M. A. Psychological Interventions with Siblings of Pediatric Cancer Patients: A Systematic Review. *Psychooncology* **2009**, *18* (12), 1241–1251. https://doi.org/10.1002/pon.1565.
34. Yelton, L.; Forbis, S. Influences and Barriers on Physical Activity in Pediatric Oncology Patients. *Front. Pediatr.* **2016**, *4*, 131. https://doi.org/10.3389/fped.2016.00131.
35. Patel, D. R.; Luckstead, E. F. Sport Participation, Risk Taking, and Health Risk Behaviors. *Adolesc. Med.* **2000**, *11* (1), 141–155.
36. Reddon, H.; Meyre, D.; Cairney, J. Physical Activity and Global Self-Worth in a Longitudinal Study of Children. *Med. Sci. Sports Exerc.* **2017**, *49* (8), 1606–1613. https://doi.org/10.1249/MSS.0000000000001275.
37. Speyer, E.; Herbinet, A.; Vuillemin, A.; Briançon, S.; Chastagner, P. Effect of Adapted Physical Activity Sessions in the Hospital on Health-Related Quality of Life for Children with Cancer: A Cross-over Randomized Trial: Physical Activity in Children With Cancer. *Pediatr. Blood Cancer* **2010**, *55* (6), 1160–1166. https://doi.org/10.1002/pbc.22698.

38. Hinds, P. S.; Hockenberry, M.; Rai, S. N.; Zhang, L.; Razzouk, B. I.; Cremer, L.; McCarthy, K.; Rodriguez-Galindo, C. Clinical Field Testing of an Enhanced-Activity Intervention in Hospitalized Children with Cancer. *J. Pain Symptom Manage.* **2007**, *33* (6), 686–697. https://doi.org/10.1016/j.jpainsymman.2006.09.025.
39. *COVID-19 pandemic triggers 25% increase in prevalence of anxiety and depression worldwide*. Who.int. https://www.who.int/news/item/02-03-2022-covid-19-pandemic-triggers-25-increase-in-prevalence-of-anxiety-and-depression-worldwide (accessed 2023-01-09).
40. Chatterjee, S. S.; Barikar C, M.; Mukherjee, A. Impact of COVID-19 Pandemic on Pre-Existing Mental Health Problems. *Asian J. Psychiatr.* **2020**, *51* (102071), 102071. https://doi.org/10.1016/j.ajp.2020.102071.
41. Bemis, H.; Yarboi, J.; Gerhardt, C. A.; Vannatta, K.; Desjardins, L.; Murphy, L. K.; Rodriguez, E. M.; Compas, B. E. Childhood Cancer in Context: Sociodemographic Factors, Stress, and Psychological Distress among Mothers and Children. *J. Pediatr. Psychol.* **2015**, *40* (8), 733–743. https://doi.org/10.1093/jpepsy/jsv024.
42. Carriere, R.; Adam, R.; Fielding, S.; Barlas, R.; Ong, Y.; Murchie, P. Rural Dwellers Are Less Likely to Survive Cancer - An International Review and Meta-Analysis. *Health Place* **2018**, *53*, 219–227. https://doi.org/10.1016/j.healthplace.2018.08.010.
43. Utsey, S. O.; Hook, J. N. Heart Rate Variability as a Physiological Moderator of the Relationship between Race-Related Stress and Psychological Distress in African Americans. *Cultur. Divers. Ethnic Minor. Psychol.* **2007**, *13* (3), 250–253. https://doi.org/10.1037/1099-9809.13.3.250.
44. Warner, E. L.; Kirchhoff, A. C.; Nam, G. E.; Fluchel, M. Financial Burden of Pediatric Cancer for Patients and Their Families. *J. Oncol. Pract.* **2015**, *11* (1), 12–18. https://doi.org/10.1200/JOP.2014.001495.
45. Santacroce, S. J.; Kneipp, S. M. A Conceptual Model of Financial Toxicity in Pediatric Oncology. *J. Pediatr. Oncol. Nurs.* **2019**, *36* (1), 6–16. https://doi.org/10.1177/1043454218810137.
46. Williams, L. K.; Lamb, K. E.; McCarthy, M. C. Behavioral Side Effects of Pediatric Acute Lymphoblastic Leukemia Treatment: The Role of Parenting Strategies: Parenting and Child Behavior. *Pediatr. Blood Cancer* **2014**, *61* (11), 2065–2070. https://doi.org/10.1002/pbc.25164.
47. Kim, H.; Zhou, E. S.; Chevalier, L.; Lun, P.; Davidson, R. D.; Pariseau, E. M.; Long, K. A. Parental Behaviors, Emotions at Bedtime, and Sleep Disturbances in Children with Cancer. *J. Pediatr. Psychol.* **2020**, *45* (5), 550–560. https://doi.org/10.1093/jpepsy/jsaa018.
48. Bendor, S. J. Anxiety and Isolation in Siblings of Pediatric Cancer Patients: The Need for Prevention: The Need for Prevention. *Soc. Work Health Care* **1990**, *14* (3), 17–35. https://doi.org/10.1300/J010v14n03_02.
49. Brett K. M. & Davies, E. M. B. What Does It Mean? Sibling and Parental Appraisals of Childhood Leukemia. *Cancer Nursing* **1988**, *11*, 329–338.
50. Gogan, J. L., & Slavin, L. A. Intervening with Brothers and Sisters. In *The Damocles Syndrome*; Koocher, G.P., & O'Malley, J.E., Ed.; McGraw-Hill: New York, NY, 1981; pp 101–111.
51. Martinson, I. M.; Gilliss, C.; Colaizzo, D. C.; Freeman, M.; Bossert, E. Impact of Childhood Cancer on Healthy School-Age Siblings. *Cancer Nurs.* **1990**, *13* (3), 183–190. https://doi.org/10.1097/00002820-199006000-00008.
52. Walker, C. L. Stress and Coping in Siblings of Childhood Cancer Patients. *Nurs. Res.* **1988**, *37* (4), 208–212. https://doi.org/10.1097/00006199-198807000-00004.
53. Ford, S.; Fallowfield, L.; Lewis, S. Can Oncologists Detect Distress in Their Out-Patients and How Satisfied Are They with Their Performance during Bad News Consultations? *Br. J. Cancer* **1994**, *70* (4), 767–770. https://doi.org/10.1038/bjc.1994.393.
54. Ringnér, A.; Jansson, L.; Graneheim, U. H. Parental Experiences of Information within Pediatric Oncology. *J. Pediatr. Oncol. Nurs.* **2011**, *28* (4), 244–251. https://doi.org/10.1177/1043454211409587.
55. Valrie, C.; Thurston, I.; Santos, M. Introduction to the Special Issue: Addressing Health Disparities in Pediatric Psychology. *J. Pediatr. Psychol.* **2020**, *45* (8), 833–838. https://doi.org/10.1093/jpepsy/jsaa066.