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The Evaluation of Change in Psychosocial Risk With Caregivers of Children With Chronic Kidney Disease: A Short-term Longitudinal Mixed-Methods Study

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Abstract

Background: The COVID-19 pandemic and its accompanying safeguards intensified many of the ongoing daily challenges faced by caregivers of young people with chronic kidney disease (CKD) both pre-transplant and post-transplant, and also created a variety of new and pressing concerns. Little is known about how these families managed this unexpected adversity in their lives.

Objective: To evaluate change in psychosocial risk for families of young people with CKD during the COVID-19 pandemic health emergency from the perspective of caregivers.

Design: A short-term longitudinal mixed-methods study with a convergent parallel design.

Setting: Manitoba, Canada.

Participants: Thirty-six caregivers of young people with CKD participated in a quantitative assessment prior to the pandemic; approximately half were transplant recipients. Thirteen were re-assessed during the pandemic (62% were caregivers of transplant recipients) using both qualitative and quantitative assessments.

Methods: First, caregivers completed the Psychosocial Assessment Tool (PAT) prior to the pandemic. Second, caregivers were re-assessed using the PAT during the pandemic. They were also interviewed about their experiences. Changes in PAT scores over time were evaluated, including an investigation of whether psychosocial risk was related to transplant status. Interviews were coded using thematic analysis. In the interpretation stage, the qualitative findings were combined with the quantitative results to help explain the latter and reach a more fulsome understanding of caregivers' experience.

Results: Quantitatively, overall family psychosocial risk scores increased significantly during the pandemic health emergency, as did the domain of Caregiver Problems. Families of transplant recipients were found to be at significantly lower psychosocial risk pre-pandemic than families of transplant candidates. Coding identified Negative Pandemic Experiences, Positive Pandemic Experiences, and Coping Mechanisms. Mixed-methods analyses revealed several areas of convergence and divergence between the quantitative and qualitative findings.

Limitations: Limitations included a small sample size that limited generalizability, single site data collection, and single caregiver report.

Conclusions: Although overall family psychosocial risk increased during the pandemic, caregivers described several resilience processes and characteristics. A mixed-method approach provided a unique perspective that highlighted the value of integrating quantitative and qualitative findings. Results were discussed within the pediatric psychosocial preventive health model framework.

Keywords

chronic kidney disease, mixed methods, psychosocial risk, resilience, caregivers, COVID-19, pandemic, mental health

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Introduction

Pediatric chronic kidney disease (CKD) is increasingly common. It is currently estimated to affect between 30 and 100 million children globally.[1] Caregivers of children and young people with CKD are often at risk for a variety of psychosocial challenges, such as depression, anxiety, interpersonal problems, and high stress levels.[2,3] The World Health Organization declared a global health emergency due to the COVID-19 pandemic in March 2020; this emergency was declared over in May 2023. This unprecedented situation and its accompanying safeguards intensified many of the daily challenges faced by these caregivers and also created a variety of new and pressing concerns.[4] It is important to better understand how these families managed this unexpected adversity in their lives, as clear linkages have been identified in this population between pandemic-related experiences, psychosocial functioning, and health outcomes.[5]

A limited number of quantitative studies have addressed the psychosocial functioning of families of children with CKD during the pandemic health emergency. For example, an online survey of Chinese caregivers found that a small minority reported anxiety and depression in the clinical range very early (February 2020) in the pandemic.[6] Another study of Canadian caregivers conducted a longitudinal comparison using a standardized assessment of family functioning conducted prior to the pandemic, with a later assessment conducted during the first few months (August to December 2020).[7] They found that, on average, family functioning improved during the pandemic based on reports by caregivers and young people over the age of 12; however, it should be noted that variability in responses increased significantly (more than twice as much) during the pandemic assessment. This increased variability suggests that the complexity of family functioning during the pandemic may not have been adequately captured by this brief standardized assessment alone.

Some qualitative work has focused on the pandemic-related experiences and well-being of children and young people who received heart and lung transplants[8] and their caregivers.[9] Very little research has included both quantitative and qualitative assessments of psychosocial risk and well-being. Recent survey-based investigations of caregivers of children with CKD in India[4] and the United Kingdom[10] as well as Spanish caregivers of children who received solid organ transplants[11] included both open-ended and closed questions that addressed caregiver psychosocial well-being during the first year of the pandemic health emergency (these surveys were conducted from June to October, 2020, in May 2020; and from July to August, 2020, respectively). Taken together, these 3 studies found that many caregivers reported high levels of stress during the pandemic, with some reporting depressive and anxiety symptoms in the clinical range on standardized measures. Caregivers also expressed understandable apprehension about life-threatening aspects of the pandemic for their child with CKD, as well as for themselves and other family members.

These studies provided important information concerning family psychosocial well-being early in the pandemic; however, they were not longitudinal in nature and therefore could not assess if or how psychosocial risk changed during the pandemic. In addition, they did not use a mixed-methods approach that integrated qualitative and quantitative findings. To address this issue, the present study used a short-term longitudinal convergent parallel mixed-methods design which synthesized quantitative and qualitative findings to better understand the nature of psychosocial risk in families of children with CKD during the emergency phase of the COVID-19 pandemic. Given recent quantitative findings concerning families of children with chronic illness or medical complexity,[12] we expected a significant increase in overall family psychosocial risk during the pandemic.[13] We further explored if transplant status was related to psychosocial risk, as past research has suggested that transplant success is positively associated with more positive mental health and well-being for family members.[14] Using qualitative methods, we investigated caregiver perspectives on their pandemic-related experiences, with a focus on better understanding both positive and negative aspects, as well as on their coping mechanisms; this is in contrast to previous exploratory work.[15] Finally, we explored potential areas of convergence and divergence between quantitative and qualitative findings, in order to further expand our understanding of changes in family psychosocial risk and well-being during the pandemic beyond the findings of quantitative and qualitative findings alone.

In summary, the primary aims of the present mixed-methods study were to (1) assess stability and change in the quantitative assessment of psychosocial risk for families of young people with CKD during the COVID-19 pandemic health emergency using the Psychosocial Assessment Tool (PAT), (2) to investigate positive and negative aspects of caregiver pandemic-related experiences and coping mechanisms using

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a qualitative approach, and (3) to discover how the integration of these 2 strands of evidence provided a more fulsome understanding of the nature of psychosocial risk for these families during the COVID-19 pandemic.

Materials and Methods

The present short-term longitudinal study was conducted at 2 time points. Quantitative data was collected in-person at the first time point from July 2018 to January 2019, and both quantitative and qualitative data were collected virtually at the second time point from March 2021 to November 2022. Data collected at the first time point was part of a clinical quality improvement study; therefore, oral assent was obtained. Approval for data collected at the second time point was granted by the University Health Research Ethics Board (HS24290) and all participants provided written informed consent in accordance with the ethical standards of the Declaration of Helsinki 1975, revised Hong Kong 1989.

Recruitment

Recruitment targeted families seeking kidney care from a Canadian children's hospital. All primary caregivers of a child (under the age of 18 years) with CKD were approached by a research assistant during their routine hospital clinic visit; no other inclusion criteria were applied. All who were approached agreed to participate. At time 2, all time 1 caregivers received letters of invitation. It should be noted that 3 (8%) of time 1 families were not available for later recruitment at time 2 due to death of the CKD patient (n = 1) and lack of contact information due to geographic relocation (n = 2). See Table 1 for detailed demographic information.

Data Collection

Data collection at time 1 was conducted in-person following routine hospital clinic appointments. Data collection at time 2 was conducted using virtual platforms (eg, Zoom; Microsoft Teams); a $75 honorarium was provided at time 2 only. Open-ended semi-structured interviews were recorded and transcribed verbatim.

Demographic Information

Caregivers were asked to provide demographic information about their family (eg, child age, relationship status) at time 1 and time 2. To address any possible literacy/ESL (English as a Second Language) issues, the research assistant provided as much assistance as needed (eg, reading questions aloud).

Table 1. Clinical and Demographic Data of Caregivers and Their Families.

	Time 1 (N = 36)	Time 2 (N = 13)
Mean child age (y)	12.38 (5.08)	15.39 (5.54)
Child gender		
Female at birth	56%	38%
Transplant recipient	53%	62%
Time since transplant (mo)	66.63 (63.20)	9.3 (4.48)
Mean caregiver age (y)	43.97 (9.68)	49.45 (6.73)
Caregiver type		
Biological mother	86%	85%
Caregiver relationship status		
Partnered	89%	77%
Ethno-cultural background		
Indigenous	53%	15%
European	33%	69%
Asian	8%	8%
Middle Eastern	3%	8%
Latino	3%	0%
Mean number of children	2.8 (1.3)	2.9 (1.5)

Psychosocial Assessment Tool

Caregivers completed the PAT at both time points. The PAT is a validated standardized screening tool for psychosocial risk in families of children with chronic illness that was originally developed for families of oncology patients.[16] A total score is calculated by summing all 7 domain subscales: family structure/resources, social support, patient/child problems, sibling problems, caregiver problems, caregiver stress reactions, and family beliefs. Each domain score is calculated by adding the risk factors endorsed by the caregiver divided by the total number of risk items for the subscale. The total PAT score is used to determine the level of family risk (Universal [low risk]: some risk factors, many resources; Targeted [medium risk]: moderate risk factors, moderate resources; Clinical [high risk]: many risk factors, few resources) based on the Pediatric Psychosocial Preventative Health Model.[17] A modified version of PAT 3.0[18] was used for the present study which included questions concerning CKD after consultation with the original PAT developers. To address any possible literacy/ESL issues, the research assistant provided as much assistance as needed (eg, reading questions aloud).

Semi-structured Interviews

At time 2 during the emergency phase of the pandemic (between March 2021 and November 2022), caregivers were asked open-ended questions during a virtual one-on-one interview conducted by an experience single interviewer using a trauma-informed approach. Questions invited caregiver perspectives concerning how the pandemic affected their child, their family, and themselves. Interview recordings were transcribed verbatim, using virtual platform AI-assisted transcription.

Quantitative Data Analysis

Descriptive statistics were used to summarize characteristics of caregivers and their families. Student's paired *t*-tests were used to compare mean total PAT scores and each domain over time. Linear ordinary least squares (OLS) univariable regression analyses were used to assess if transplant status was a significant predictor of the total PAT score at time 1 only; the sample size at time 2 precluded similar analyses. The potential association between transplant status and level of psychosocial risk was assessed using chi-square analyses. The significance level was set at $P = .05$.

Qualitative Data Analysis

Thematic analysis (TA) was used to analyze the interview transcripts. Thematic analysis is a systematic process involving 6 steps that is used to create an analytical narrative of the data.[19] Coders first familiarized themselves with the data and then utilized an inductive approach to generate initial codes. In the present study, 2 coders carried out initial coding separately and independently. Codes were clustered and collapsed into draft themes.[20] These were then reviewed with a patient partner for relevant shared meaning. During the final phase, team members who had provided both virtual and in-person care of young people with CKD during the pandemic reviewed themes to determine whether further revisions were needed. Discrepancies in coding were resolved and the meanings of themes were further clarified through these discussions.

Trustworthiness was established by attending to the credibility, transferability, dependability, and confirmability of the data.[21] To address credibility, we conferred with a patient partner during the coding process. Transferability to other settings and populations was addressed by providing a detailed description of the context in which the present study findings were generated so that others can determine whether application to other contexts is appropriate.[21] Dependability was enhanced by the long-term professional relationship between one of the lead coders (a health care professional) and the caregivers, as well as the involvement of a patient partner who was a caregiver of a child with CKD.[21] Confirmability was undertaken by using direct quotes as evidence of the findings. It should be noted that qualitative analyses were previously undertaken on the same data set[15]; however, these analyses were more exploratory in nature, rather than a specific focus on positive and negative aspects of pandemic experience and coping mechanisms, as in the present study.

Mixed-Methods Data Analysis (QUAL + QUAN)

Mixed-methods analyses followed a convergent parallel design which followed 4 procedural steps.[22] The core assumption of this approach is that when QUAL data (eg, interviews) and QUAN data (eg, statistical results) are integrated, it is possible to offset the limitations of each type of data and leverage their strengths in order to provide a more complete understanding of the research problem than either approach alone can provide.[22] First, qualitative and quantitative data were collected separately as described above—that is, one dataset did not depend on the results of the other. Next, the 2 sets of data were analyzed separately and independently from each other using specific qualitative and quantitative analytic procedures. It should be noted that the qualitative results were reported in detail elsewhere.[15] In step 3 or the interpretation stage, findings of these 2 separate sets of data were integrated by directly comparing and contrasting them. In the final step, the extent to which and in what ways the 2 sets of results converged or diverged with each other was examined in order to provide a more comprehensive and multifaceted understanding of caregiver experiences during the pandemic.

Results

Study Population

All eligible families seeking care at the Children's Hospital were invited to participate at time 1; all who were invited agreed to participate.

Descriptive Characteristics

At time 1, 36 caregivers completed the PAT; approximately half (n = 19 or 53%) were caregivers of transplant recipients. At time 2, 13 caregivers participated; the majority (n = 8 or 62%) were caregivers of transplant recipients. See Table 1 for detailed demographic information.

Quantitative Data Analysis

The PAT Total mean score increased significantly over time (see Table 2), indicating that family psychosocial risk increased during the pandemic. A comparison of domain mean scores over time indicated that Caregiver Problems was the only domain to increase significantly over time, with a small effect size (Cohen's $d = 0.17$).

In terms of describing the levels of family risk according to the Pediatric Psychosocial Preventative Health Model (PPPHM),[17] before the pandemic 47% (n = 17) of families were categorized as low risk (Universal), while 42% (n = 15) of families were categorized as moderate risk (Targeted) and 11% (n = 4) were categorized as high risk (Clinical). Of those who were re-assessed at time 2,

Table 2. A Comparison of Mean Domain Scores of the Psychosocial Assessment Tool Over Time.

PAT domains	Time 1 (N = 36)	Time 2 (N = 13)	Statistic	*P* value
Overall PAT score	1.19	1.47	*t*(12) = 2.13	.05
Caregiver stress	0.14	0.22	*t*(12) = −0.96	.36
Caregiver problems	0.21	0.31	*t*(12) = −2.14	.05
Child problems	0.34	0.36	*t*(12) = −0.29	.77
Sibling problems	0.21	0.20	*t*(12) = 0.05	.96
Social support	0.00	0.15	*t*(12) = −1.98	.07
Structure and resources	0.19	0.12	*t*(12) = 1.56	.15
Family beliefs	0.14	0.11	*t*(12) = 1.01	.33

Table 3. Regression Testing First-Order Effects of Transplant Status on Overall Psychosocial Adjustment at Time 1.

Time 1 predictors	β	*SE* (β)	*b*	*P*	Adj. R^2	*F*	*df*	*P*
Constant	-	0.16	1.41	<.001	0.08	4.18	1.34	.049
Transplant status (TS)	–.33	0.23	–0.46	.049				

54% (n = 7) of families remained in the same risk category as time 1; for those that changed, 38% (n = 5) were at increased risk and 8% (n = 1) were at lower risk than before the pandemic.

At the first time point prior to the pandemic health emergency, we further investigated if families of post-transplant patients were at lower psychosocial risk. Our analysis indicated that this was indeed the case; post-transplant status was a significant predictor of the PAT Total score, accounting for 8% of the variance (see Table 3). In addition, transplant status was significantly associated with PPPHM risk category χ^2 (N = 36) = 7.49, *P* = .02 with a large effect size Cramer's *V* = 0.5. Families of transplant recipients at time 1 were more likely to be categorized in the lowest risk group (Universal) (n = 13) than transplant candidates (n = 5) (66.7%-27.8%). In addition, families of transplant candidates were more likely to be categorized as moderate risk (Targeted) (n = 9) (50%-33.3%) and as high risk (Clinical) (n = 4) (22.2%-0%) than families of transplant recipients. See Figure 1.

Qualitative Data Analysis

Coding of the interview transcripts identified 3 themes: (1) Negative Aspects of the Pandemic, (2) Positive Aspects of the Pandemic, and (3) Coping Mechanisms. Each is briefly described below and direct quotes that illustrate each theme are provided in Table 4.

Negative Aspects of the Pandemic

Caregivers identified a multitude of negative aspects of the pandemic. They experienced significantly elevated anxiety regarding their child's health during the emergency phase of the pandemic and reported that their children also experienced heightened anxiety. They expressed serious concern regarding the risk of exposure to and/or testing positive for COVID-19 for themselves and their children. Some acknowledged that past fears and traumatic stress related to their child's chronic illness were exacerbated by their pandemic experiences. Many caregivers found that reduced contact with extended family members due to public health restrictions or their own caution concerning exposure to COVID-19 was a significant issue, because both formal and informal parenting supports were reduced or eliminated. They mentioned feeling stressed by increased child supervision or care responsibilities due to the increased isolation. Some reported feeling burned out or overwhelmed by increased caregiving responsibilities. For some, the quality of their family relationships was also negatively affected by the pandemic, due to increased demands for support.

Disruptions in routine, including work, school, and health care, also reduced family quality of life. Sudden shifts to remote learning for their child elevated concerns about potentially negative impacts on learning, school performance, and social engagement. Some caregivers reported the shift to remote work was disruptive and the transition required adjustment. Others expressed frustration concerning remote care that replaced or reduced in-person health care, including apprehension regarding potentially delayed or canceled treatment due to the pandemic. And although caregivers understood the reason for public health restrictions, some expressed sadness and loss concerning canceled events and missed milestones, along with the social interactions that accompanied them.

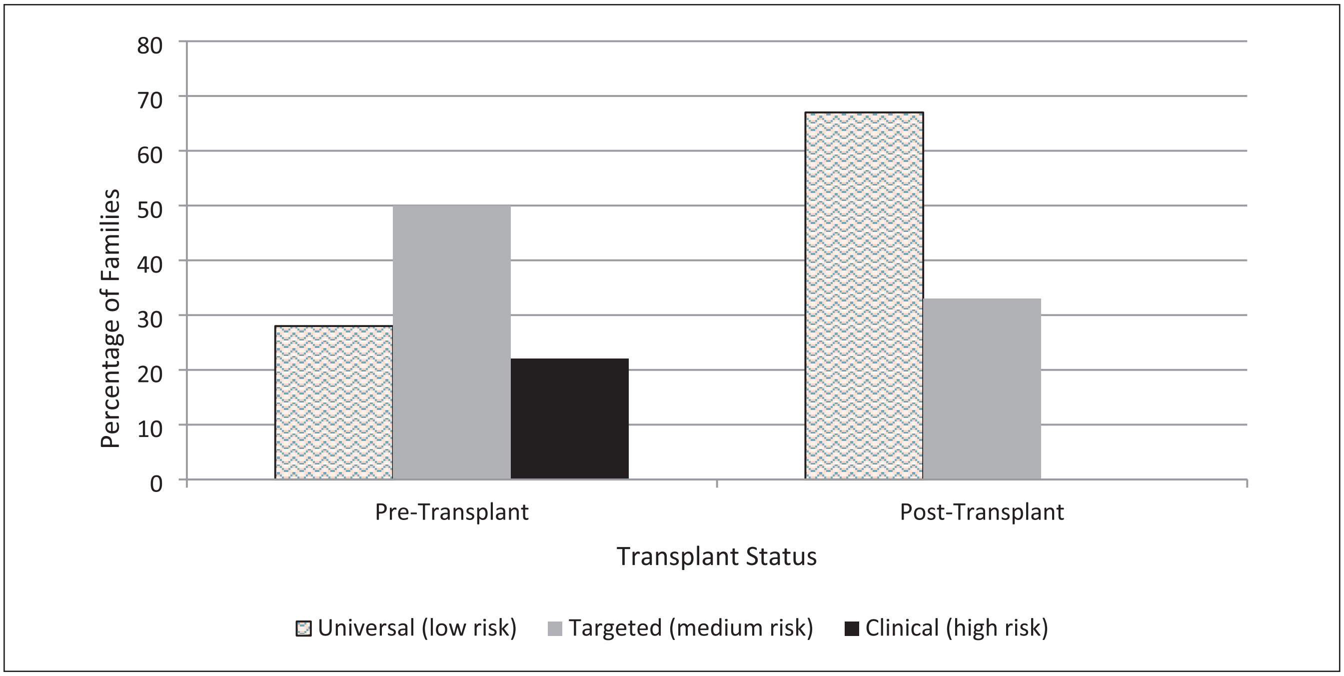

Figure 1. A comparison of risk categories for families of transplant candidates and recipients at time 1.

Positive Aspects of the Pandemic

Caregivers also identified several positive impacts of their pandemic experience. Some felt that family relationships were more cohesive due to more time spent together in shared activities. Remote work offered benefits for some caregivers as well, including greater convenience such as less commuting time and expense. Caregivers reported some young people preferred remote education, as they received increased personal attention from teachers, or greater peace of mind related to lower exposure risk. Similarly, some families found remote health care and flexible care options to be comforting because of the reduced exposure risk.

Positive Coping Mechanisms

Caregivers identified several positive coping strategies that they used to help manage their pandemic-related concerns. One important coping mechanism was accessing social support, which applied to themselves as well as their family members. Finding ways to stay in touch during the pandemic virtually or in compliance with public health restrictions (eg, outdoors) helped to ease feelings of social isolation. Another coping mechanism was cultivating appreciation for positive aspects of their experience, such as valuing quiet time alone. During the emergency phase of the pandemic, caregivers also limited their exposure to media in order to reduce feelings of stress and uncertainty. Finally, caregivers mentioned that taking public health precautions to reduce and/or manage health risks promoted feelings of comfort and protection.

Mixed-Methods Analysis

Following a convergent parallel design, quantitative (QUAN) and qualitative (QUAL) findings were synthesized by identifying areas of convergence and divergence.[22] See Table 5 for a summary of results.

The first area of convergence concerned increased psychosocial risk and caregiver anxiety. The PAT domain of Caregiver Problems significantly increased during the pandemic; this domain addressed a variety of concerns, including anxiety, family relationships, and other aspects of family functioning. These QUAN findings converged with the QUAL Negative Aspects of the Pandemic theme in which caregivers expressed significant anxiety concerning the potential negative effects of the pandemic on their own and their child's health, as well as on their work, school, and health care experiences. This finding highlighted the serious negative impacts of the pandemic on caregiver mental health and well-being in a detailed and comprehensive manner.

A second area of convergence concerned social support. The QUAN finding that the domain of Social Support remained stable over time indicated that caregivers did not perceive the levels of support they received before or during the pandemic as problematic. This finding converged with the QUAL theme of Positive Aspects of the Pandemic in which caregivers discussed the social support they and young people alike received from outside the family, including peers at school and extended family members despite the physical isolation imposed by pandemic-related restrictions. For some, support was also received from positive relationships within the family.

Table 4. Thematic Analyses Results.

Theme	Caregiver direct quotes
Negative aspects of the pandemic	
Caregiver anxiety	"Of course one gets scared that this thing enters their home, and they get sick or the kids get sick . . . we found it difficult." P12
Patient anxiety	"He felt very threatened that he would be dying within the next few months for sure . . . so we tried to reassure him–you are safe at home." P11
Risk of exposure	"My concern is not to get sick and die." P10
Trauma response	"Sometimes I can talk about it, and I can't sometimes. I find myself going back through the situation and remembering everything that happened to the detail." P5
Increased isolation	"So, I was looking after both the kids (alone) all the time because he (partner) doesn't feel comfortable having someone else in our house." P1
Increased demands	"Sometimes it's absolutely overwhelming." P3
Family relationships	"I'm the one supporting everybody . . . and they kind of support me back. But I'm the one, you know." P11
Remote learning	"During the pandemic he had online classes, so our work was little bit harder because we were always watching him and telling him to study." P7
Remote work	"There was a period of adjustment when he was home a lot. He has gone back to work now in the last few months." P1
Health care	"They just call her on the phone so nobody actually sees her." P2
Delayed care	"My biggest worry right now is because of the backlog . . . everything's going to be slowed down to the point where we can't do the transplant." P6
Public health	"Kids need to have normal life; they need to see friends and everyone's being stuck together was hard. They're bored a lot." P5
Positive aspects of the pandemic	
Family cohesion	"It (spending time together) just made us gel as a family more." P8
Remote work	"I get to work from home so yay that's good right?" P4
Remote school	"He was okay; yeah, absolutely he prefers it that way." P9
Health care	"So, I said it's okay, and we have to tell your team that this is your wishes, if we can postpone, we'll try to postpone this. When he understood that he's safe and people respect his choice I think he felt more at ease." P11
Positive coping mechanisms	
Social support	"The people that he hangs out with are his friends and he's very happy with that . . . so that's a good thing." P6
Appreciation	"I really treasure and value my quiet time." P8
Limiting media	"I stopped watching the daily updates because they change every week, they're different, and nobody can predict what's going to happen." P4
Taking precautions	"I was talking to my physician and he asked me 'How do you guys do with masks?' and I said 'We wear them all the time.'" P10

Table 5. Mixed-Methods Integration.

Quantitative findings	Qualitative findings
Areas of convergence	
Increased overall psychosocial risk & increased caregiver problems	Negative aspects of the pandemic including heightened caregiver anxiety
Stable and low social support	Positive aspects of the pandemic including social support from outside the family and positive family relationships
Stable and high child problems	Negative aspects of the pandemic including increased parenting demands, less parenting support, and disrupted routines
Stable and low sibling problems	Positive aspects of the pandemic and coping caregiver stress, social support, mechanisms, such as family cohesion and family structure and resources, and cultivating appreciation family beliefs
Areas of divergence	
Association between post-transplant status and higher psychosocial risk	Transplant status not discussed

A third area of convergence concerned child problems and parenting. The most endorsed PAT domain was Child Problems both before and during the pandemic emergency; it remained high and stable over time, indicating an ongoing area of concern for caregivers. This QUAN finding partially converged with the QUAL findings within Negative Aspects of the Pandemic concerning caregiver reports of high parenting demands coupled with less access to parenting support, which amplified the burden of child care for some. A final interesting area of convergence was also observed. The QUAL findings concerning Positive Aspects of the Pandemic, such as benefits related to changes in work and school routines, and Positive Coping Mechanisms, such as cultivating appreciation, were identified despite the numerous Negative Aspects of the Pandemic that were mentioned. These positive aspects, which must be appreciated in the context of multiple negative aspects, converged with the QUAN finding of stability across several domains assessed by the PAT over time (eg, low scores in the domains of Caregiver Stress, Sibling Problems, Structure and Resources, and Family Beliefs).

One area of divergence that was identified concerned transplant status. The QUAN finding indicated a significant association between transplant status and caregiver psychosocial well-being at time 1; pre-transplant status accounted for a small but significant amount of variance in pre-pandemic psychosocial risk. In contrast, QUAL findings indicated that during their interviews, caregivers did not identify transplant status as playing an important role in their well-being or their pandemic experience.

Discussion

The present mixed-methods investigation of the impact of the COVID-19 global health emergency on families of young people with CKD yielded several important findings which permitted a more holistic understanding of their experiences. Areas of convergence highlighted the role of heightened caregiver anxiety and parenting challenges amid the unrelenting adversities imposed by the pandemic, but results also emphasized the importance of family relationships, as well as other positive aspects which reflected individual and family resilience processes. It is important to note that in the present study only one third of the original sample was re-assessed during the pandemic; however, these families were categorized into a variety of risk levels, suggesting that not only those who were doing well returned for assessment.

The increase in overall family psychosocial risk found in the present study aligned with other work that demonstrated a high degree of psychosocial risk for families managing pediatric chronic illness during the pandemic.[12,23] When directly comparing the PAT results obtained in the present study with previous findings, it is not surprising that the overall mean score of our returning sample appeared higher than mean scores obtained pre-pandemic in other studies with families of pediatric kidney transplant recipients,[24] pediatric hematopoietic stem cell transplant recipients,[25] and children with medical complexity.[26] However, it is striking that the overall mean score of our returning sample also appeared to be higher than PAT Total scores obtained during the pandemic with caregivers of children with medical complexity[12] and with a child in cancer treatment.[23] Although our sample size precluded conducting a statistical comparison of PAT scores with these other studies, our PAT scores appear to be one of the highest for any cohort published in the literature to date.[12,23-26] It should be noted that our findings of increased psychosocial risk contrast those of a recent study that found improved family functioning in families of children with nephrotic syndrome during the pandemic.[7] This difference may be attributable to differences in assessment tools, or in timing of data collection, as this study was conducted earlier in the pandemic than the present study. In addition, it is unclear how many young people in this study were transplant recipients, which may have influenced results.

According to the PPPHM,[17] approximately half of the returning sample in the present study remained in the same pre-pandemic risk category when re-assessed during the pandemic health emergency, while a significant minority scored in a higher risk category during the pandemic than before. It was therefore *not* the case that only caregivers and families who were doing well returned to participate during the pandemic; however, it is important to note that a majority of those who returned were caregivers of transplant recipients. Previous research has found that higher levels of well-being are often reported by families post-transplant,[27] although length of time since transplant is important to take into account, as the first year post-transplant is considered a high risk period for graft failure[28] and often involves frequent monitoring and medication changes. It should be noted that families who returned to participate at the second time point were less than 1 year post-transplant on average, suggesting they were facing many of these specific challenges. While post-transplant status was associated with lower family psychosocial risk prior to the pandemic in the present study, it is important to note that the average length of time since transplant for those families was much longer (>5 years). It may therefore not be surprising that caregivers in our sample who responded at the second time point during the pandemic did not identify transplant status as a significant issue in their open-ended interviews as they were focused on more pressing issues related to the first year of post-transplant care. A more specific focus on the post-transplant process and its potential development into a protective factor for psychosocial risk may be an important area for future qualitative research to explore.

In addition to a significant increase in overall family psychosocial risk, the domain of Caregiver Problems increased significantly over time. This domain incorporated a wide variety of concerns, including caregiver feelings of anxiety and depression, relationship issues, physical and mental health problems, and stressful family events such as suicide attempts, criminal justice system experiences, and substance-related problems. This quantitative finding converged with qualitative findings concerning caregiver reports of their significantly elevated anxiety during the pandemic, mostly due to health-related concerns for their child with CKD, as well as other negative aspects of their pandemic experiences, such as disruptions to family, work and school routines, employment loss and disruption, concerns about access to health care and pandemic-related delays, and even discrimination suffered in relation to preventive health measures such as vaccination. This convergence paralleled previous work that found heightened caregiver anxiety and distress during the pandemic[4,6,10] and illuminated how specific aspects of caregivers' pandemic-related experience elevated their psychosocial risk.

The most endorsed PAT domain by caregivers at both time points was Child Problems, which remained high and stable over time. In fact, the levels of child problems reported before and during the pandemic were strikingly similar and were parallel to caregiver reports in other studies involving families of children with medical complexity during the pandemic.[12] This PAT domain addressed behavioral, cognitive, and social problems that the young person with CKD may be experiencing[24] and in this sample, these concerns remained pressing as the pandemic unfolded. This quantitative finding converged with qualitative results that described pandemic stressors for young people in detail, such as the sudden shifts to virtual health care and education, increased social isolation due to social distancing or school lockdowns, as well as missed family events and milestones, all of which likely amplified the child problems experienced by caregivers. Our findings also support previous qualitative work that found young people with CKD struggled with the impacts of pandemic-related lockdowns.[10]

Most PAT domains remained stable over time, including Sibling Problems, Caregiver Stress, Social Support, Family Structure and Resources, and Family Beliefs. These quantitative findings converged with qualitative findings that identified positive aspects of caregivers' pandemic experiences, including greater family cohesion, appreciation of positive aspects of remote work and schooling, and feeling supported by health care systems and protected by preventive public health measures. This convergence indicated that, despite the extraordinary circumstances created by the pandemic, many caregivers continued to effectively manage the daily challenges they typically faced—an important finding that suggests individual and family resilience processes were at work.[29,30] These processes included positive coping strategies such as cultivating appreciation, maintaining supportive relationships, enhancing family cohesion, and acknowledging that some unanticipated pandemic-related changes to work, school, and health care brought benefits rather than disruption. Taken together, this convergence illustrated the hardiness of caregivers in the face of serious and unprecedented adverse circumstances.[29,30] It should be noted that mean Social Support and Caregiver Stress scores did increase at the second time point, but these increases were not statistically significant, likely due to the reduced sample size.

Limitations

The present study had several strengths and limitations that need to be taken into account. First, our longitudinal mixed-methods approach is unique in the literature. Our findings not only provided important information about stability and change in family psychosocial risk, they also provided a more holistic understanding of how and why psychosocial risk increased in some domains but not others. However, it is important to note that both the generalizability of our findings and the potential for type 2 error were significantly affected by the small pre-pandemic sample size, and the even smaller sample of caregivers who returned for re-assessment during the pandemic. Our examination of the potential effects of transplant status on psychosocial risk were also affected by our sample size, as important covariates such as age at diagnosis could not be included or controlled for in the regression analyses. It should also be noted that the ethno-cultural background of our pre-pandemic and post-pandemic samples differed in terms of a higher proportion of families of European origin and a lower proportion of Indigenous families at the second time point. Our sample did not include families of infants, toddlers, or preschoolers with CKD, and our sample of caregivers was predominantly female, which may have limited the generalizability of our findings to families with younger children and to other carers. In addition, because the majority of our sample included caregivers of transplant recipients, the experience of pre-transplant families may not have been adequately captured in our results.

Our findings have several important implications for research and practice. While the present study was an important first step, further longitudinal research is needed that examines the long-term educational, socioemotional, and mental health impacts of the pandemic on all family members. Future work should include families with children of a wide variety of ages who are in various phases of their transplant journey, and whenever possible, the perspectives of young people should be considered to provide a more holistic understanding of family functioning. Our findings demonstrated that health care providers may benefit from the use of standardized screening tools such as the PAT to help identify those families at higher risk in order to prioritize psychosocial resources. Given how pandemic experiences were reminiscent of previously high stress medical situations for some families, a trauma-informed approach by health care providers would allow the opportunity to provide more effective care.[31]

Conclusions

In summary, although our work showed the heavy toll that the pandemic health emergency took on caregivers in terms of heightened anxiety and significantly increased family psychosocial risk, it also highlighted caregiver strengths and resilience in the face of serious adverse circumstances. Our mixed-methods longitudinal analysis provided a more complete picture of how and why psychosocial risk increased than quantitative or qualitative findings could each provide alone, demonstrating that while some areas of concern worsened during the pandemic, others remained stable at high or low levels. These findings underscore the importance of ongoing psychosocial assessment with caregivers of children with CKD to better understand their strengths as well as areas they may need support.

Ethics Approval and Consent to Participate

Ethical approval was granted by the Health Research Ethics Board at the University of Manitoba. All participants provided written informed consent.

Consent for Publication

All the authors provide consent for publication.

Availability of Data and Materials

The data are available from the corresponding author upon reasonable request.

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Author Contributions

C.C.P. participated in research design, the conduct of the research, data analysis, and in the writing of the manuscript. K.K. participated in data analysis and in the writing of the manuscript. J.S. participated in research design, data analysis, and in the writing of the manuscript. A.G. participated in research design and in the writing of the manuscript. A.K. participated in the writing of the manuscript. K.P. participated in the conduct of the research and in the writing the manuscript. G.R. participated in research design and in the writing of the manuscript. A.G. participated in research design and in the writing of the manuscript.

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