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# Parents' Experiences of Childhood Cancer During the COVID-19 Pandemic: An Australian Perspective

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## Abstract

**Introduction** COVID-19 has had far-reaching impacts including changes in work, travel, social structures, education, and healthcare. **Objective** This study aimed to explore the experiences of parents of children receiving treatment for cancer during the COVID-19 pandemic. **Methods** Parents whose children were currently in treatment for childhood cancer or had completed treatment in the previous 12 months, participated in semi-structured interviews, face-to-face or via teleconferencing. Thematic analysis was used to analyze the data. **Results** The sample consisted of 34 participants (17 fathers and 17 mothers) from all states across Australia. Median age 37.5 years (range 29–51, years, SD = 6.3). Five main themes were identified: “Welcome to the Club”; “Remote Work and Study”; “Silver Linings”; “The Loneliest Experience” with three sub-themes “Immediate Family”; “Friends”; and “Overseas Family” and “Lack of Support” with two sub-themes: “Community Support” and “Organized Support.” **Conclusion** These findings revealed contrasting experiences of the impact of the COVID-19 pandemic. For parents whose children were neutropenic, the pandemic provided benefits in increased community understanding of infection control. Parents also reflected that the movement to remote work made it easier to earn an income. In contrast, some parents observed that restrictions on visitors and family intensified feelings of isolation. Parents also described how the COVID-19 reduced access to support services. These findings contribute to an understanding of the multifaceted impacts of the COVID-19 pandemic on families of children with cancer.

**Key words:** Australia; cancer; childhood; COVID-19; neutropenia; pediatric; qualitative.

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## Introduction

In January 2020, the World Health Organization (WHO) declared COVID-19 a pandemic (WHO, 2021). The impact of COVID-19 has been significant in terms of loss of life with countries such as the USA, Brazil, India, Italy, and the UK experiencing a large number of cases and high mortality rates (WHO, 2021). Research has demonstrated that COVID-19, and the resultant loss of friends and family, health impacts, hospitalizations, restrictions, economic, and societal changes, have led to psychosocial effects including increasing rates of distress, depression, and anxiety (Torales et al., 2020).

The impact of COVID-19 has, however, varied considerably internationally, with many countries having comparable low case rates and mortality per head of the population (WHO, 2021). Australia case-load has been relatively low with 30,610 cases and 910 deaths between April 5, 2020 and June 30 2021 (Commonwealth Department of Health, 2021). Governmental responses to the pandemic have also varied significantly. In the Australian context, strict measures were implemented, both at a state and nationwide level, to reduce the potential for outbreaks (Murphy & Karp, 2020). These measures included border closures, meaning that Australians, with few exceptions, could not leave Australia, overseas tourists were prohibited from entering, and interstate travel was limited (Murphy & Karp, 2020). Australian states went into periods of lockdowns which included home-schooling, remote online work, closure of entertainment venues, social distancing rules, and mask mandates. Returning overseas Australians were also required to pay for 2 weeks in government-managed hotel quarantine. This system had some failures and some states experienced longer lockdowns due to community transmission from returned overseas Australians. Changes occurred within the healthcare system as hospitals were restructured to ensure that they were prepared for any urgent COVID-19 medical needs. Hospitals also introduced measures to reduce risks to vulnerable patients including restricting visitor/volunteer access.

## Background

Every year in Australia ~1,000 children aged 0–18 years will be diagnosed with cancer and it remains the leading cause of death by disease in children (Australian Institute of Health and Welfare (AIHW), 2021). A diagnosis of childhood cancer is a difficult experience for both the child and their parents, and studies have found that parents exhibited moderate–severe post-traumatic stress symptoms (PTSS) and anxiety and depression after a childhood cancer diagnosis (Kazak et al., 2005; Sulkers et al., 2015; Vrijmoet-

Wiersma et al., 2008). Children undergoing cancer treatment often require complex treatment protocols including lengthy hospitalizations, outpatient appointments, surgeries, and therapies. This can create practical challenges for parents, particularly mothers, who often have to reduce working hours or stop work altogether (Wakefield et al., 2014). Fathers have also been shown to experience stress in balancing demands of work and caring for their child with cancer and their siblings (Brody & Simmons, 2007).

Siblings are also impacted by the experience and research has shown that they often meet the criteria for post-traumatic stress (PTS) or post-traumatic stress disorder (PTSD) and have a poorer quality of life (QoL) (Kaplan et al., 2013; Long et al., 2018). Children receiving cancer treatment often become neutropenic, making them vulnerable to infectious diseases. This fear of infection impacts all family members and siblings have to miss social activities and school due to concerns about transmitting infections to the child with cancer (Long et al., 2018).

Due to the unknown risk of COVID-19 to children with cancer, and their neutropenic status, pediatric oncology wards across Australia restricted ward access for visitors and families (Kotecha, 2020; Sullivan et al., 2020).

Given the novel nature of COVID-19, there is still a paucity of data on the psychosocial impacts of the pandemic on families of children diagnosed with cancer. A Dutch study by van Gorp et al. (2021) examined data from childhood oncology outpatient clinics and found no difference in quality of life before the COVID-19 pandemic compared to during the early pandemic. Interestingly, they also found that fewer caregivers were distressed during early COVID-19 compared with pre-COVID-19. In contrast, a study by Darlington et al. (2020) conducted in England during lockdown found that 85% of parents/caregivers of childhood cancer patients were worried about the virus and 69.6% felt that the hospital was not a safe place. The study concluded that COVID-19 had increased parents/caregivers' anxiety and concerns about their child's care. This study found very few positives except for families feeling closer and "feeling safe at home." Similarly, researchers from Italy have concluded that restrictions in hospital access increased parents' psychosocial distress (Zucchetti et al., 2020).

## Rationale

This study is part of a larger study which uses the ecological systems theory as a lens to explore the experiences of those affected by childhood cancer (Bronfenbrenner, 2009). Ecological systems theory is a useful heuristic for understanding the wide-reaching impact of childhood cancer as it seeks to account for both the context and complexity of individual experiences (Bronfenbrenner, 2009). This theory posits that a person's well-being is

dependent on interrelated and complex factors within the social system within which they sit and necessitates an examination of the social supports both formal and informal (Bronfenbrenner, 2009). The ecological systems theory also provides a conceptual framework for articulating the necessity to look at the context surrounding the family of a child diagnosed with cancer and highlights the need for any analysis of childhood cancer to include an examination of the larger social context, including major social/health crisis such as the COVID-19 pandemic (Darling, 2007).

These are unprecedented times and there is little understanding of the impact of the various societal changes that have occurred due to COVID-19. Much of the research to date regarding COVID-19 and pediatric oncology has understandably occurred in countries with high rates of COVID-19 and there has been limited research that explores the experiences of those living in countries with low infection and mortality rates (Casanova et al., 2020). Although restrictions that were introduced in countries with low rates were necessary to maintain low levels of COVID-19, it remains unknown how the societal changes and restrictions have impacted families of children diagnosed with cancer (Sullivan et al., 2020). It is important to understand how COVID-19 has impacted families whose children have been diagnosed with cancer so that appropriate supports can be put in place to minimize potential negative effects.

### Objective

This study aimed to explore the experiences of Australian parents of children receiving treatment for cancer during the COVID-19 pandemic.

### Methods

The research was approved by a University Human Research Ethics Committee in March 2021 (HRE2021-0119). All participants were provided with study information and completed written consent and demographic forms.

This study employed phenomenological approach using a qualitative design (Forrester, 2010; van Manen, 2017). The rationale for using a phenomenological approach is that allows for an exploration of the hidden meanings and enables an understanding of participants' lived experiences (Forrester, 2010). A qualitative methodology has been chosen for this study as this approach recognizes the importance of individuals' point of view and allows people to describe and relate their feelings and responses. This provides a rich in-depth understanding of peoples' experiences and enables the development of practices and policies that meet the needs of the community (Leavy, 2017). The study collected data via

semistructured face-to-face interviews. This method of gathering data is more flexible and allows for a natural way of interacting, assisting participants to clearly discuss issues as they understand them.

Participants were parents of children aged 17 years or under who were currently in treatment or had completed treatment for childhood cancer in the previous 12 months. Participants were recruited via notices placed between March and June 2020 on Facebook sites and distribution of flyers via multiple organizations and groups that support families of children diagnosed with cancer. Purposeful and snowball sampling were also used to ensure different perspectives were gained. Participants were recruited from across Australia to ensure that broad perspectives were explored including from states that experienced longer COVID-19 lockdowns. Semi-structured interviews, using an interview guide as a framework, were conducted by the first author and interviews were digitally recorded. The interview guide was a flexible document and questions were developed in response to early analysis, examples include "could please describe how COVID-19 impacted your experiences of childhood cancer treatment?" and "Did hospital restrictions impact your experience and if so how?" On average interviews lasted 66.2 min (range, 41–93 min, SD = 14). At the completion of the interview, participants were provided with information on support services and a \$20 gift card.

Sample size was not predetermined but based on previous qualitative research it was envisaged sample size would range between 20 and 30 interviews (Mason, 2010). Saturation was achieved after approximately the 26th interview. Additional prescheduled interviews were conducted to ensure that no new themes were emerging. We also considered the depth and richness of the data when deciding to cease interviewing. Transcription was completed either online via computer rev.com software or manually by the first author, as soon as possible after the interview. Interviews completed via online software were reviewed and necessary changes made. Participants were given pseudonyms and individual identifiable factors removed.

This study followed incorporated multiple measures in order to ensure rigor including the completing a reflexive journal during data collection and analysis to record personal observations, and responses to data to enable awareness of any personal reactions/bias (Berger, 2015).

### Data Analysis

Data were thematically analyzed using Braun and Clarke's six-phase process (Braun & Clarke, 2006). Thematic analysis is a method of analyzing qualitative data which allows for the identification of common themes and patterns across data. Initially, all

interviews were listened to by the first author to develop familiarization and this also provided opportunity to review transcripts for accuracy and make any necessary amendments.

All transcripts were then read, and initial reflections were recorded. Initial analysis was used to shape ongoing data collection and refining of questions (Pope et al., 2000). The transcripts were then reviewed to look for common patterns. After several readings of transcripts, the main coder developed initial codes and a codebook was developed. This process relied on a paper-based system of coding. The manual process is considered to provide a thorough and comprehensive understanding of the data (Pope et al., 2000). A selection of transcripts was then reviewed by co-coder. Codes were discussed by all members of the research team and any disagreements were discussed until consensus was reached. Transcripts were then reread to generate, name, and define themes (Braun & Clarke, 2006). At this stage, a thematic map was developed to graphically represent findings (Pope et al., 2000). All authors reviewed the thematic map and provided feedback on the final themes and subthemes.

### Participants

A total of 34 parents: 17 fathers and 17 mothers with a median age of 37.5 years (range 29–51 years,

SD = 6.3 years) were interviewed. Twenty-six children were currently receiving treatment, whereas 8 children had completed treatment. The average time since completion of treatment was 56 days (range 2–168 days). All children were still being monitored by hospital-based oncology including scans and blood tests. The age of the child at diagnosis ranged from 4 hours to 15 years. Participants were recruited from all states in Australia, with 76% ( $N=26$ ) living in the metropolitan area and 24% ( $N=8$ ) living in outer metropolitan/rural regions. Demographic information including race and ethnicity were self-reported by participants. Participants were asked to indicate which ethnicity they identified with, and categories were based on previous studies conducted in Australia and informed by broad categories from the Australian Bureau of Statistics. Table I demonstrates participant demographics.

### Findings

From, the interviews, five themes were identified: “Welcome to the Club”; “Remote Work and Study”; “Silver Linings”; “The Loneliest Experience” with three sub-themes “Immediate Family”; “Friends”; and “Overseas Family” and “Lack of Support” with two sub-themes: “Community Support” and “Organized Support.” A thematic map graphically represents findings (Figure 1).

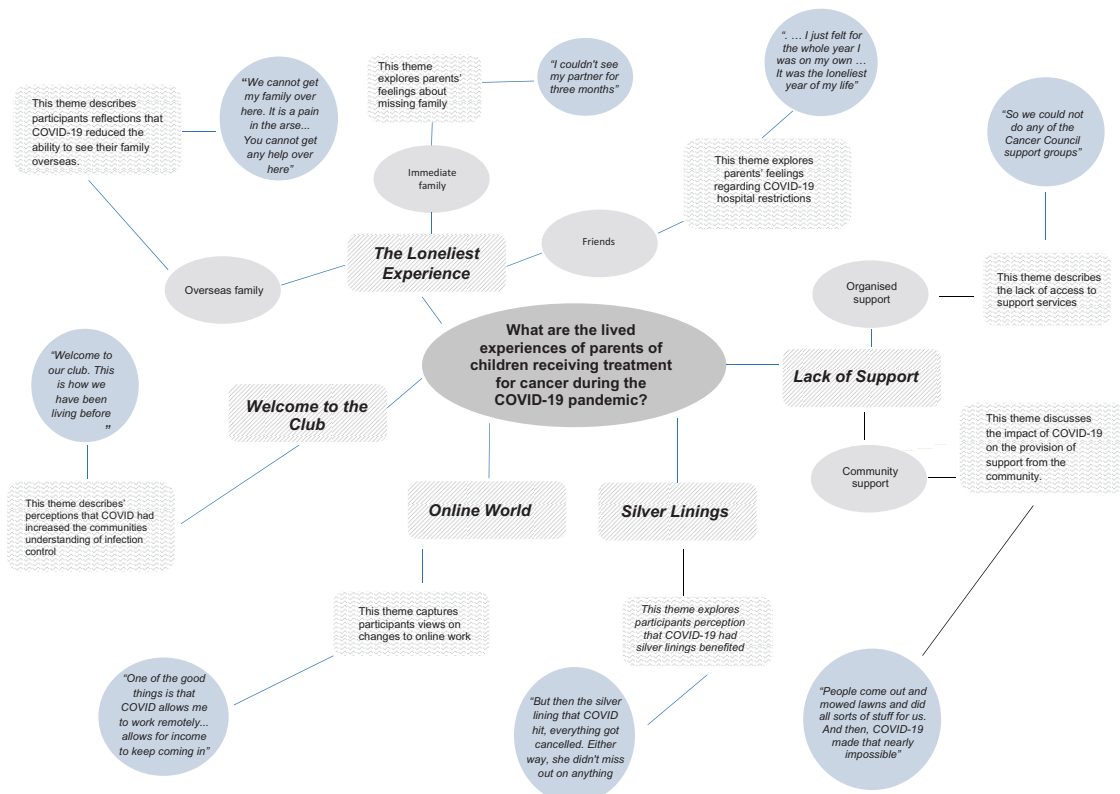


Figure 1. Thematic map.

**Table I.** Sample Sociodemographics (N = 34 Participants)

	N	%
Parent's gender		
Male	17	50
Female	17	50
Marital status		
Married	30	88
Divorced	1	3
De-facto	3	9
Education		
Year 10	2	6
Year 12	4	12
TAFE/trade college	7	21
Bachelor	14	41
Post-graduate	7	21
Participant's ethnic identification		
European	8	24
South American	1	3
Australian	23	68
Asian	1	3
African	1	3
Primary carer of a child with cancer		
Mother	18	53
Father	3	9
Shared	13	38
Child's primary diagnosis		
Brain tumor	3	9
Sarcoma	3	9
Hematological <sup>a</sup>	18	52
Neuroblastoma	4	12
Lymphoma	3	9
Other	3	9
Child's gender		
Male	19	56
Female	15	44
Siblings		
0	4	12
1	16	47
2	10	29
3	2	6
>4	2	6

<sup>a</sup>Hematological includes, acute lymphocytic leukemia (B and T cells), acute myeloid leukaemia, congenital acute lymphocytic leukemia.

### Welcome to the Club

This theme describes the sentiment amongst participants that the widespread changes that occurred because of COVID-19 mirrored their existing experiences of childhood cancer. Many participants expressed that the fear of infection that the general community was now experiencing was a normal way of life for parents of children with cancer. One father joked: "It's part of a running joke...welcome to our world" and another commented, "welcome to our club. This is how we have been living before COVID-19." Childhood cancer treatment and immune suppression had meant living in isolation with one mother commenting: "it didn't impact us so much because we didn't actually see people that often anyway...because you always try to keep in a bit of a bubble because he's so unwell...and social outings were...non-

existent." One dad commented "COVID lockdowns feel like what life is like in treatment."

Participants commented that the awareness of the need for infection control by the general community reduced the risk to their children. With one father stating

"when you have an...immunosuppressed child...you have to be very cautious in terms of contacting other people...We were struggling because people wouldn't care...When COVID happened, they started taking care...social distancing, wiping everything, covering the mouths."

Another father commented: "It's actually positively impacted us. We found that...she wasn't getting colds and flu...she would normally get." COVID-19 also meant that some parents were able to stay home during lockdowns which reduced the risk of infections to their children and simplified conversations: "We actually...enjoyed it...he was so compromised with his immune system. It was easier rather than having someone turn up with a snuffle...and having to say 'Sorry, you cannot come in'...we did not have to have any difficult conversations."

### Remote Work and Study

This theme captures participants' perceptions that the move towards remote work that occurred in response to COVID-19 was beneficial. Working remotely, in several cases, reduced the financial burden. One father observed: "One of the good things is that COVID allows me to work remotely...It's a big weight off my shoulders...allows for income to keep coming in...if it had happened in 2019 it would have been a different approach." The introduction of online schooling also made caring for siblings less complicated "Yeah, it was easier...Because of COVID-19, we were home-schooling the kids as well" describing this process as "less hassle with getting them to school." Being able to home-school siblings meant that many of the demands and complexities of juggling siblings' schooling and extracurricular activities were reduced.

### Silver Linings

This theme explores participants' perception that COVID-19 had silver linings that benefited them and their children. One example was that many participants perceived that COVID-19 made it easier for their children to miss out on school and events "She couldn't go to school, that was hard, but then the silver lining that COVID hit, everything got canceled. Either way, she didn't miss out on anything because everybody missed out." Participants also expressed that the widespread societal changes reduced their sense of being anomalous with one father commenting "everyone is wearing masks...We do not feel like we are the odd one out." When discussing the restrictions on visitors some participants also noted that it

increased the bond with healthcare professionals. One mother commented that it was “okay because we had formed a fantastic relationship with the staff.” Several participants also highlighted what they described as “small benefits” such as ease of parking and reduced travel time due to roads being less congested due to remote work.

### The Loneliest Experience

This theme investigates parents’ feelings regarding COVID-19 restrictions which includes three sub-themes, immediate family, friends, and overseas family members.

#### Immediate Family

This sub-theme identifies participants’ reflections that restrictions meant that partners and siblings could not visit during lockdowns. One father commented that only being allowed one parent on the ward was “one of the worst parts of the cancer experience” explaining “. . . I couldn’t see my partner for three months . . . five minutes at the door of the hospital . . . a little kiss and good night, that was horrible.” Participants also reflected that being away from siblings was difficult, with one mother describing missing siblings “My little one. . . I couldn’t help him with his online learning. . . his homework. . . I had a Year 12 and a Year 11. They had to fend for themselves . . . The guilt . . . I can’t begin to tell you.” This loneliness was particularly pronounced for those who received a diagnosis during the tight lockdown rules. Seen in one mother’s reflection:

The main impact of COVID. . . was firstly only one parent being able to accompany a child in ED at a time. This meant the very first moment we discovered (child’s diagnosis) I was sitting alone and (husband) was in the ED waiting room. I then stayed with (child diagnosed with cancer) it meant we were left to process this news solo and not together. . . When I heard (child’s diagnosis) the last thing I wanted was to sit with my own thoughts. Hearing that and having to phone (husband) in the waiting room to tell him. . . just made the situation even more stressful.

#### Friends

This sub-theme explores the impact of ward visitor restrictions. Some participants reflected that not having visitors made it a difficult experience “I spent every day in the hospital. . . for the whole year I was on my own. . . It was the loneliest year.” Participants described how COVID-19 meant that normal social interactions became impossible with one participant describing how they “really needed that extra bit of just sitting down, and having a coffee, and just sharing.” This isolation was not just confined to parents and some participants reflected that the isolation also impacted their children. With one mother commenting: “I think the impact on (child diagnosed with cancer) was that he very much lived in an adult

world for 12 months because there weren’t any siblings or peers.”

#### Family Overseas

This sub-theme outlines the impact of having borders closed. Several participants noted that one of the challenges of navigating childhood cancer during COVID-19 was that it prevented overseas family members from visiting Australia to support them “we cannot get my family over here. It is a pain in the arse. . . My mum would love to come out and help out.” For some, this lack of family support seemed to have made them feel they were alone in the experience “We definitely felt like we’re kind of in the trenches, just the three of us. That was because COVID, just because of travel restrictions.”

#### Lack of Support

This theme discusses the impact of COVID-19 on the provision of support and has two sub-themes: “Community support” and “Organized support.”

#### Community Support

This sub-theme outlines some participants reflections that COVID-19 meant that support from friends and the local community was limited, with one participant commenting: “People come out and mowed lawns and did all sorts of stuff for us. And then, COVID-19 made that nearly impossible with lockdowns.” Another commented: “I did find that it dried up as COVID went on. . . because nobody could see each other, and everybody was busy at home trying to work or school their own kids.”

#### Organized Support

This sub-theme describes the lack of access to normal support services which impacted the whole family “Because it was last year, it was COVID, so we could not do any of the. . . support groups.” COVID-19 restrictions also resulted in less access to ward services. When discussing support services one parent commented “a lot of the stuff that I think they do to keep the kids’ spirits up. . . All that stopped completely.” Several participants also commented that there were indirect impacts on support services such as lack of access to community-based psychological health services due to the increased demand and lack of access to allied health services due to restrictions.

#### Discussion

Here, we report the experiences of Australian parents whose children were receiving cancer treatment during the COVID-19 pandemic. The study demonstrates that the impact of COVID-19 was multifaceted with parents describing both positive and negative impacts.

This contrasts with previous COVID-19 research within the pediatric oncology setting in countries with high rates of COVID which reported minimal positive effects (Alshahrani et al., 2020; Darlington et al., 2020).

Consistent with previous childhood cancer research, parents in this study described how fear of normal infections, such as colds, was a significant cause of anxiety whilst their children were undergoing treatment (Yildirim Sari et al., 2013; Young et al., 2002). Participants highlighted that in many ways COVID-19 mediated this fear, and they reflected that COVID-19 had increased people's awareness of the need for infection control measures thus reducing the risk to their children. For some, particularly, those in long-term treatment involving chemotherapy the pandemic provided a simplified life as the community modified their behavior which meant that participants did not need to educate people about infection control. Although the need for infection control and change to lifestyle for the general population has undeniably been a negative experience, for families whose children are receiving treatment for cancer it has made them feel less "different." Parents also discussed that they felt that the community could now relate to their anxiety regarding infections. Our report highlights the toll that standard immune suppression and infection risk measures have on families of children diagnosed with cancer including the loss of social life, fear of infections, limitations on community interactions, and need for hygiene measures. The COVID-19 pandemic has made such measures normal for the general population and in doing that has shed light on childhood cancer family's experiences during treatment.

Childhood cancer has been shown to have a detrimental impact on parents' income (Kelada et al., 2020). Often one parent must cease working to care for a child with cancer and one parent; usually, the father continues to work to provide income meaning they are unable to be with their child in hospital. Research has also shown that the balancing of work and family can create a sense of conflict for fathers (Brody & Simmons, 2007). In this study, parents observed that the change to remote online work, which came about due to COVID-19 meant that parents could work and earn an income while providing care for their children. Previous research has shown that mothers provide most of the care in hospital (Al-Gamal et al., 2019; Wilford et al., 2019). Although this seemed to be the case in this study, it also appears that COVID-19 has increased the ability of fathers to share the care for the child in hospital whilst working remotely.

There are multiple stressors for families of children diagnosed with cancer including the loss of normal life, challenges in balancing the needs of the siblings,

and maintaining normal parental relationships (Cox, 2018; Van Schoors et al., 2018). Previous reports have shown that siblings of children with cancer experience poor QoL (Long et al., 2018). Parents in this study reported that COVID-19 exacerbated these challenges and increased the burden on siblings as it reduced normal family interactions including the ability for siblings to visit the ward thus making an already difficult situation more challenging.

In contrast to the study in England by Darlington et al. (2020), which indicated that parents felt very fearful of COVID-19, in our study, parents did not express significant concerns regarding the threat of COVID-19 to their children or themselves. These differing results possibly reflect that the Darlington study was conducted during a lockdown when England was experiencing high caseloads/mortality rates. There also appears to be differences in fear of COVID-19 between the adult and pediatric cancer settings. Australian research within the adult oncology setting found that 53% of cancer patients/carers reported significant psychological distress associated with fear of COVID-19 (Edge et al., 2021). Fear of COVID-19 may have been lower among our sample because carers of children with cancer often live restricted lifestyles due to fear of infection and are thus isolated from the outside world which may have provided parents with a sense of safety from COVID-19.

One area of concern regarding COVID-19 and the restrictions on visitors on the ward relates to those families whose children were diagnosed during periods of reduced access. Clarke and Fletcher (2003) contended that the manner of disclosure regarding the diagnosis is profoundly important to parents. Several parents in this study described the experience of learning their child had cancer without the support of their partner. For these families, the COVID-19 restrictions increased distress.

An important finding of this study relates to COVID-19 increasing parents' sense of isolation and loneliness. Previous research has found that parents of children experience psychological distress as a result of their child's treatment (Al-Gamal et al., 2019; Compas et al., 2015). Studies have found that parents exhibited PTSS, anxiety, and depression after a childhood cancer diagnosis (Kazak et al., 2005; Sulkers et al., 2015; Vrijmoet-Wiersma et al., 2008). Research has highlighted that family support systems can help mitigate negative psychological experiences among parents of children with cancer (Fuemmeler, et al., 2003). Our study shows that COVID-19 prevented many parents from receiving support from family and friends. This raises concerns regarding the lack of support provided to these families which may have increased parents' and siblings' psychological distress, predisposing them to an increased risk of PTSS.

### Study Limitations and Future Research

There are a number of limitations in this study. First, the majority of the participants were married/coupled. This may be reflective of additional time constraints of single parents and thus availability for interviews. In addition, the majority of participants were of Australian or European ancestry, thus reducing the generalizability of the study. Reports have revealed that people from culturally and linguistically diverse communities (CALD) have disproportionately been impacted by COVID-19 (Mamluck & Jones, 2020). It would therefore be valuable to further explore the effects of COVID-19 within Australian CALD communities. Another potential limitation of this study is that the low rates of infection and mortality in Australia compared with other parts of the world may mean that these findings may not be relevant or applicable to countries that have experienced higher rates of infection. One area of interest for future research would be to assess the well-being of parents of children diagnosed with cancer during the COVID-19 pandemic to determine if restrictions affected their long-term psychological wellbeing.

### Clinical Implications

This study has revealed measures that can be introduced to assist families of children receiving treatment for cancer both during the current pandemic and long term. This study suggests that additional measures need to be taken to support families of children with cancer when restrictions prevent both parents from being on the ward. This may include the integration of teleconferencing into clinical care so that information can be disseminated to both parents simultaneously, reducing the burden on one parent to relay distressing news. It is also important that those who received a diagnosis during lockdown are identified, provided with assessment and psychological support to manage the additional stress associated with the timing of the diagnosis.

In future, the understanding that COVID-19 restrictions are similar to the restrictions faced by families of immunocompromised children with cancer may facilitate communication between these families and the wider community about expectations and provision of support. Public health and education measures regarding COVID-19 have increased Australians' understanding of the need for basic infection control and hygiene measures. In the long term, this understanding can be used to educate the population regarding immune suppression in children receiving cancer treatment. This understanding may be particularly useful in an educational setting, where schools can be encouraged to adopt similar measures used during the COVID-19 pandemic to assist families of children who are neutropenic. COVID-19 had necessitated that society become adept at the use

of technology for work and social interaction. Our findings underscore that this has been a positive aspect of COVID-19 for many families of children with cancer, allowing them to continue work and education without disruption. The online infrastructure COVID-19 has created could be used to assist families of children with cancer.

### Conclusion

This is one of few Australia-wide studies to examine the impact of COVID-19 on families of children diagnosed with cancer. This study provides an understanding of the impact of COVID-19 restrictions and societal changes on families whose children were receiving cancer treatment. It shows that COVID-19 has had substantial impacts both positive and negative. Interestingly, there did not appear to be any difference in experiences or concerns in different states across Australia. This study underscores the significant and life-changing impact of a child's cancer diagnosis on families. Although the general population have found the changes and social isolation implemented because of COVID-19 difficult to adjust to, families in this study found that they were similar to changes they experience while their children were in treatment. This provides insight into the experiences of families whose children are receiving treatment for cancer which will assist in improved understanding and ultimately enhanced delivery of supports to families. Our findings also provide vital information to understand the negative consequences of COVID-19 restrictions and societal changes which will enable appropriate supports to be provided to families of children who are being treated for cancer. It is hoped that the understandings developed can be used to ensure that in the long-term families of children who have been diagnosed with cancer are provided with appropriate support to manage both the routine aspects of childhood cancer and the added burdens arising from the restrictions imposed due to COVID-19.

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## References

- Al-Gamal, E., Long, T., & Shehadeh, J. (2019). Health satisfaction and family impact of parents of children with cancer: A descriptive cross-sectional study. *Scandinavian Journal of Caring Sciences*, 33(4), 815–823. <https://doi.org/10.1111/scs.12677>
- Alshahrani, M., Elyamany, G., Sedick, Q., Ibrahim, W., Mohamed, A., Othman, M., Al Thibani, N., Alsuhaibani, O., Al Amro, M., Gharawi, A., Al Sharif, O., Elborai, Y., Alabbas, F., Binhassan, A., AlMoshary, M., Al Mussaed, E., & Alkhayat, N. (2020). The impact of COVID-19 pandemic in children with cancer: A Report from Saudi Arabia. *Health Services Insights*, 13(13), 1178632920984161. <https://doi.org/10.1177/1178632920984161>
- Australian Institute of Health and Welfare (AIHW). (2021). *Cancer Data in Australia*; Canberra: AIHW. <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia>.
- Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15(2), 219–234. <https://doi.org/10.1177/1468794112468475>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Brody, A., & Simmons, L. (2007). Family resiliency during childhood cancer: The father's perspective. *Journal of Pediatric Oncology Nursing*, 24 (3), 152–165. <https://doi.org/10.1177/1043454206298844>
- Bronfenbrenner, U. (2009). *Ecology of human development*. Harvard University Press. <https://doi.org/10.1016/j.cpr.2005.10.002>
- Casanova, M., Pagani Bagliacca, E., Silva, M., Patriarca, C., Veneroni, L., Clerici, C. A., Spreafico, F., Luksch, R., Terenziani, M., Meazza, C., Podda, M., Biassoni, V., Schiavello, E., Chiaravalli, S., Puma, N., Bergamaschi, L., Gattuso, G., Sironi, G., Massimino, M., & Ferrari, A. (2020). How young patients with cancer perceive the COVID-19 (coronavirus) epidemic in Milan, Italy: Is there room for other fears? *Pediatric Blood & Cancer*, 67(7). <https://doi.org/10.1002/pbc.28318>
- Clarke, J., & Fletcher, P. (2003). Communication issues faced by parents who have a child diagnosed with cancer. *Journal of Pediatric Oncology Nursing*, 20(4), 175–191. <https://doi.org/10.1177/1043454203254040>
- Commonwealth Department of Health. (2021). *Coronavirus (COVID-19) at a glance infographic collection*. <https://www.health.gov.au/resources/collections/coronavirus-covid-19-at-a-glance-infographic-collection>.
- Compas, B. E., Bemis, H., Gerhardt, C. A., Dunn, M. J., Rodriguez, E. M., Desjardins, L., Preacher, K. J., Manring, S., & Vannatta, K. (2015). Mothers and fathers coping with their children's cancer: Individual and interpersonal processes. *Health Psychology*, 34(8), 783–793. <https://doi.org/10.1037/hea0000202>
- Cox, T. (2018). Caregivers reflecting on the early days of childhood cancer. *European Journal of Cancer Care*, 27(1), e12499. <https://doi.org/10.1111/ecc.12499>
- Darling, N. (2007). Ecological systems theory: The person in the center of the circles. *Research in Human Development*, 4(3–4), 203–217. <https://doi.org/10.1080/15427600701663023>
- Darlington, A., Morgan, J., Wagland, R., Sodergren, S., Culliford, D., Gamble, A., & Phillips, B. (2020). COVID-19 and children with cancer: Parents' experiences, anxieties, and support needs. *Paediatric Blood & Cancer*, 68(2), e28790. <https://doi.org/10.1002/pbc.28790>
- Edge, R., Mazariego, C., Li, Z., Canfell, K., Miller, A., Koczwara, B., Shaw, J., & Taylor, N. (2021). Psychosocial impact of COVID-19 on cancer patients, survivors, and carers in Australia: A real-time assessment of cancer support services. *Supportive Care in Cancer*, 29(9), 5463–5473. <https://doi.org/10.1007/s00520-021-06101-3>
- Forrester, M. (2010). *Doing qualitative research in psychology*. Sage.
- Fuemmeler, B., Brown, R., Williams, L., & Barredo, J. (2003). Adjustment of children with cancer and their caregivers: Moderating influences of family functioning. *Families, Systems & Health*, 21(3), 263–276. <https://doi.org/10.1037/1091-7527.21.3.263>
- Kaplan, L., Kaal, K., Bradley, L., & Alderfer, M. (2013). Cancer-related traumatic stress reactions in siblings of children with cancer. *Families, Systems & Health*, 31(2), 205–217. <https://doi.org/10.1037/a0032550>
- Kazak, A., Boeving, C., Alderfer, M., Hwang, W., & Reilly, A. (2005). Posttraumatic stress symptoms during treatment in parents of children with cancer. *Journal of Clinical Oncology*, 23(30), 7405–7410. <https://doi.org/10.1200/jco.2005.09.110>
- Kelada, L., Wakefield, C. E., Vetsch, J., Schofield, D., Sansom-Daly, U. M., Hetherington, K., O'Brien, T., Cohn, R. J., Anazodo, A., Viney, R., & Zeppel, M. J. B. (2020). Financial toxicity of childhood cancer and changes to parents' employment after treatment completion. *Pediatric Blood & Cancer*, 67 (7), e28345. <https://doi.org/10.1002/pbc.28345>
- Kotecha, R. (2020). Challenges posed by COVID-19 to children with cancer. *The Lancet. Oncology*, 21(5), e235. [https://doi.org/10.1016/s1470-2045\(20\)30205-9](https://doi.org/10.1016/s1470-2045(20)30205-9)
- Leavy, P. (2017). *Research design* (1st edn). Guildford Press.
- Long, K. A., Lehmann, V., Gerhardt, C. A., Carpenter, A. L., Marsland, A. L., & Alderfer, M. A. (2018). Psychosocial functioning and risk factors among siblings of children with cancer: An updated systematic review. *Psychooncology*, 27 (6), 1467–1479. <https://doi.org/10.1002/pon.4669>
- Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 11(3), <https://doi.org/10.17169/fqs-11.3.1428>
- Murphy, K., & Karp, P. (2020). Borders closing. *The Guardian*. <https://www.theguardian.com/world/2020/mar/19/australian-government-moves-to-close-borders-as-new-coronavirus-cases-continue-to>
- Mamluck, L., & Jones, T. (2020). The impact of COVID-19 on black, Asian and minority ethnic communities. *National Institute for Health Research*. <https://arc-w.nihr>

- ac.uk/research-and-implementation/covid-19-response/reports/the-impact-of-covid-19-on-black-asian-and-minority-ethnic-communities.
- Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care: Analysing qualitative data. *BMJ (Clinical Research ed.)*, 320(7227), 114–116. <https://doi.org/10.1136/bmj.320.7227.114>
- Sulkers, E., Tissing, W. J. E., Brinksma, A., Roodbol, P. F., Kamps, W. A., Stewart, R. E., Sanderman, R., & Fleer, J. (2015). Providing care to a child with cancer: A longitudinal study on the course, predictors, and impact of caregiving stress during the first year after diagnosis. *Psychooncology*, 24(3), 318–324. <https://doi.org/10.1002/pon.3652>
- Sullivan, M., Bouffet, E., & Rodriguez-Galindo, C. (2020). The COVID-19 pandemic: A rapid global response for children with cancer from SIOP, COG, SIOP-E, SIOP-PODC, IPSO, PROS, CCI, and St Jude Global. *Paediatric Blood and Cancer*, 67(7), e28409. <https://doi.org/10.1002/pbc.28409>
- Torales, J., O'Higgins, M., Castaldelli-Maia, J., & Ventriglio, A. (2020). The outbreak of COVID-19 coronavirus and its impact on global mental health. *International Journal of Social Psychiatry*, 66(4), 317–320. <https://doi.org/10.1177/0020764020915212>
- van Gorp, M., Maurice-Stam H., Teunissen, L. C., van de Peppel-van der Meer, W., Huussen, M. van Meeteren, A.Y.N.S., & Grootenhuis, M. A. (2021). No increase in psychosocial stress of Dutch children with cancer and their caregivers during the first months of the COVID-19 pandemic. *Paediatric Blood and Cancer*, 68(2), 28827. <https://doi.org/10.1002/pbc.28827>
- van Manen, M. (2017). Phenomenology in its original sense. *Qualitative Health Research*, 27(6), 810–825. <https://doi.org/10.1177/1049732317699381>
- Van Schoors, M., De Mol, J., Morren, H., Verhofstadt, L., Goubert, L., & Van Parys, H. (2018). Parents' perspectives of changes within the family functioning after a pediatric cancer diagnosis: A multi-family member interview analysis. *Qualitative Health Research*, 28(8), 1229–1241. <https://doi.org/10.1177/1049732317753587>
- Vrijmoet-Wiersma, C., van Klink, J., Kolk, A., Koopman, H., Ball, L., & Maarten Egeler, R. (2008). Assessment of parental psychological stress in pediatric cancer: A review. *Journal of Pediatric Psychology*, 33(7), 694–706. <https://doi.org/10.1093/jpepsy/jsn007>
- Wakefield, C., McLoone, J., Evans, N., Ellis, S., & Cohn, R. (2014). It's more than dollars and cents: The impact of childhood cancer on parents' occupational and financial health. *Journal of Psychosocial Oncology*, 32(5), 602–621. <https://doi.org/10.1080/07347332.2014.936653>
- Wilford, J., Hopfer, S., & Wenzel, L. (2019). Perceptions of changes in clinical, informational, and supportive relationships after end of treatment among parents of young childhood cancer survivors. *Psychooncology*, 28(4), 913–919. <https://doi.org/10.1002/pon.5042>
- World Health Organization. (2021). Coronavirus (COVID-19) Dashboard. [Covid19.who.int](https://covid19.who.int). <https://covid19.who.int/>
- Yildirim Sari, H., Yilmaz, M., Ozsoy, S., Kantar, M., & Çetingul, N. (2013). Experiences of parents with the physical care needs at home of children with cancer. *Cancer Nursing*, 36(5), 385–393. <https://doi.org/10.1097/ncc.0b013e3182a0e221>
- Young, B., Dixon-Woods, M., Findlay, M., & Heney, D. (2002). Parenting in a crisis: Conceptualising mothers of children with cancer. *Social Science & Medicine*, 55(10), 1835–1847. [https://doi.org/10.1016/s0277-9536\(01\)00318-5](https://doi.org/10.1016/s0277-9536(01)00318-5)
- Zucchetti, G., Bertolotti, M., & Fagioli, F. (2020). How paediatric psycho-oncology is changing during the COVID-19 epidemic in Italy: New approaches. *Psychooncology*, 29(9), 1384–1386. <https://doi.org/10.1002/pon.5444>