School of Population Health

Discipline of Psychology

Faculty of Health Sciences

"It Changes Everything": Family Members' Experiences of Childhood Cancer

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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007, updated March 2014). The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee, Approval Number HRE2021-0119

Signature:

Date: 28th March 2024

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Dedication

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Davies, J., O'Connor, M., Halkett, G., Kelada, L., & Gottardo, N. G. (2022) Parents' experiences of childhood cancer during the COVID-19 pandemic: An Australian perspective. *Journal of Pediatric Psychology, 47*(2), 148–157. https://doi.org/10.1093/jpepsy/jsab125

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Davies, J., O'Connor, M., Halkett, G. K., Kelada, L., & Gottardo, N. G. (28th July 2022). *Fathers' experiences of childhood cancer* [Oral presentation]. Australian & New Zealand Children's Haematology/Oncology Group (ANZCHOG) Annual Scientific Meeting, Sydney, NSW, Australia.

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Davies, J., O'Connor, M., Halkett, G. K., Kelada, L., Bosco, A. M., & Gottardo, N. G. (8th March 2023) *'Torn in two': Experiences of mothers who are pregnant when their child is diagnosed with cancer* [Oral presentation]. King Edward Memorial Hospital Continuing Professional Development Courses: Midwifery Complex Care, Subiaco, WA, Australia.

Davies, J., O'Connor, M., Halkett, G. K., Kelada, L., & Gottardo, N. G. (8th November 2023). *"It changes everything": Family members experiences of childhood cancer* [Poster presentation]. Child Health Research Symposium: Perth Children's Hospital, Nedlands, WA, Australia.

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Abstract

Background

Every year in Australia, ~ 800 children aged under 15 will be diagnosed with cancer. Rates of childhood cancer have increased by 34% between 1983 and 2015 and it is estimated that rates will continue to rise in the next 20 years. Improvements in treatment protocols have meant that five-year survival rates have risen from 73% for children diagnosed between 1983-1993 to 85% between 2004-2013. These intensive treatment protocols can include a range of modalities including surgery, chemotherapy, radiation, and adjunct medications which often require long periods of hospitalisations and ongoing care in the home. Despite the increase in survival rates childhood cancer remains the leading cause of death by disease for children in Australia.

The treatments and the emotional toll of a life-threatening illness makes childhood cancer a traumatic experience for both the child and their family. Irrespective of the specific diagnosis and treatment plan, a child's cancer diagnosis profoundly affects the social and psychological well-being of all family members. Studies demonstrate that mothers and fathers of children diagnosed with cancer face significant challenges and have increased rates of depression, anxiety, and post-traumatic stress disorder (PTSD) and post-traumatic stress symptoms (PTSS). Parents of children with cancer when compared to population norms also report poorer physical health in all domains including disruption to sleep and stress related health conditions. The impact of childhood cancer can be wide-reaching and multifaceted, and the diagnosis affects many aspects of family life and family members' interactions with the wider community. Managing caregiving responsibilities and the emotional burden can isolate parents from their

social networks, making it difficult to maintain regular social interactions. Previous reports highlight distinct differences in how fathers and mothers navigate the challenges of cancer, underscoring societal norms that often position mothers as the primary caregivers during their child's treatment. Mothers generally experience high rates of psychological distress and significant disruptions to work and family routines. Fathers exhibit lower levels of psychological distress and less work disruption; however, they face distinct stressors, including having to balance work-family commitments.

Childhood cancer also creates a shift in roles and family dynamics, significantly altering 'normal life' for all family members, including siblings. The siblings of children with cancer encounter substantial effects across various facets of their lives: social, academical, friendships, schooling which they must manage whilst also grappling with their fear and grief regarding their sibling's diagnosis. Grandparents also experience profound ramifications, and their experiences in the context of childhood cancer are multifaceted, encompassing practical, psychological, and social dimensions. When a child is diagnosed with cancer, grandparents often also take on new roles to care for their other grandchildren, including taking on parental aspects such as transport to and from school, after-school activities, and sometimes moving in with the family, something which causes drastic shifts in their daily lives and familial relationships.

The experience of childhood cancer is complex. To understand childhood cancer, it is necessary to examine the individual responses of those impacted by the experience. Much of the existing research recruits' families, which often means the primary caregiver, usually the mother, acts as a proxy for the whole family, which may mask individual experiences. There is currently a dearth of research explicitly exploring the father's individual experience of childhood cancer. In addition, many of the studies on siblings have gathered data from parents, child/parent dyads, and/or oncology health professionals. Research exploring grandparents' experiences is limited and has generally focused on measurements of psychological distress or examination of communication issues and care of siblings There is a need for more research which explores individual family members experiences of childhood cancer in order to identify unaddressed needs for support and to direct further research. In addition, there is also a need to use the ecological model to develop a more nuanced understanding of the influence of social cultural norms. People sit within a larger social context that influences how they interact with and respond to the childhood cancer diagnosis. Family members are products of their social environment and are affected by gender roles and expectations that are determined by culture. An awareness of these social cultural norms and interactions will enable a more thorough understanding of family members needs and thus enable effective supports to be delivered.

Research aim

The overarching aim of this research was to use ecological systems theory as a lens to explore the experiences of individual family members (mothers, fathers, siblings, and grandparents) of children who are diagnosed with cancer. An additional aim of this research that arose in response to the COVID-19 pandemic was to explore families of children with cancer's experiences of the pandemic to identify how the pandemic impacted families of children diagnosed with cancer.

Method

This research used an interpretive paradigm using a social constructionism belief system and a hermeneutic phenomenological approach. This methodological framework was used as it aligned with the objective of understanding family members different points of view. A qualitative methodology was used as this provided an opportunity to explore people's individual experiences and gather information on their perspectives, thoughts, and feelings. The study was guided by ecological systems theory, as it provided a helpful heuristic for understanding the wide-reaching impact of childhood cancer which seeks to account for both the context and complexity of individual experiences. This study was also completed by an inside researcher who had personnel experience as the mother of a child who was diagnosed with cancer.

Participants were selected primarily by convenience sampling, with snowball sampling also used to ensure a diverse representation of families. Participants were recruited from across Australia via notices on social media sites and distribution of flyers. All family member groups (fathers, mothers, grandparents, siblings) were recruited separately in a targeted recruitment process. Interviews were conducted either in person or via web conferencing. Seventy-seven family members were recruited from across Australia. In this study, the focus was on ensuring in-depth data collection, and when it appeared that information power was achieved and the same information was being heard, recruitment ceased.

To ensure that this research had overall quality and rigour, I followed Tong et al. (2007)'s Consolidated Criteria for Reporting Qualitative Research using the criteria of creditability, transferability, dependability, and confirmability. This research used Braun and Clarke's reflexive thematic analysis (TA) as its analytical approach. TA involves six steps: developing familiarity with data, systematic data coding, generation of themes, developing and reviewing themes, review, and revision of themes, and writing-up of themes/report.

Results

Six studies examining family members experiences of childhood cancer were completed for this research. These articles explored the experiences of fathers, mothers who were pregnant when their child was diagnosed with cancer, grandparents and siblings aged under 12. It also included a study which explored family members experiences of COVID-19 and a study exploring advice from parents of children with cancer to other parents.

Seventy-seven individual family members were interviewed and the sample for this thesis consisted of:

- 21 fathers aged 33-51 years (M = 41 years, SD = 5).
- 23 mothers aged 29-50 years (M=36 years, SD = 4).
- 20 grandparents (13 grandmothers and seven grandfathers) aged from 41-77 years (M = 65 years, SD = 9).
- Thirteen siblings (seven boys and six girls) aged between 8-12 years (M = 9, SD = 1)

Findings

The major findings from six articles published or awaiting publication were as follows:

- All family members of children with cancer are impacted in various ways which are influenced by their roles and functions in the family and society.

- COVID-19 pandemic had both negative and positive impacts. Measures, such as widespread infection control (masks etc), benefited families and made them feel less alone, as others in the community could understand their sense of isolation and experienced similar changes in lifestyle. COVID-19 however decreased access to social supports both within the hospital and in the community which increased family members sense of isolation.
- A child's cancer diagnosis has a profound impact on fathers and socio-cultural norms influence fathers' experiences childhood cancer. Fathers' distress appears to have been augmented by societal pressure to remain stoic.
- Mothers who are pregnant when their children are diagnosed with cancer face additional challenges as many are required to focus on the child with cancer and they do not receive appropriate pregnancy care of support to care for the newborn child.
- Grandparents report many of the same experiences as parents and changes in demographics resulted in many having to combine working and taking care of older generations.
- Findings extend the current understanding in showing that younger siblings' developmental and cognitive skills impact their experiences of childhood cancer. Younger siblings outlined the many losses they experienced, which were shaped by developmental factors, demonstrating a need for a comprehensive and tailored programs to support siblings aged under 12 years.
- Participants in my study expressed that one of the issues that they struggled with was managing the grief associated with knowing children from other families on the ward who had died due to their cancer.

- All family members grappled with distress associated with changes to normal routines and familial roles, in addition to a broader sense of childhood cancer having disrupted their vision of their lives and the ‘natural order of things’.
- In hindsight, parents reflected that they wished they had sought out psychological support services as they were experiencing negative effects from the lack of support.

Limitation(s)

The major limitation in my study was that there were very few participants who came from culturally and linguistically diverse (CALD) backgrounds. This is a common problem with research and may reflect the complexities of recruiting families with limited English language skills who may be reluctant to participate in research conducted exclusively in English. There were also few Aboriginal and Torres Strait Islander families who participated in this research. There is a need for future studies to explore the specific experiences of CALD families and Aboriginal and Torres Strait Islander families, as they may face distinct challenges that need specific support.

Clinical implications

My research findings indicate that additional efforts are required to assist individual family members in coping with the effects of childhood cancer. This study’s recommendations include:

- The technological infrastructure such as work from home processes developed during COVID-19 needs to be used to facilitate parents’ ability to continue to work during treatment. This infrastructure and processes can also be used to facilitate increased social interaction for family members who are unable to engage in normal social interactions due to their child's neutropenia.

- It is recommended that support provided to family members should acknowledge and recognise that significant societal messages impact how people will respond to the child's cancer diagnosis. These can be both internalized and externalized messages that influence how family members behave and feel. For example, fathers need psychological support that acknowledges they receive societal messages that they need to be strong.
- Fathers need to be encouraged to connect with other fathers of children with cancer to share experiences and receive peer support.
- Pregnant mothers require a thorough assessment of their current health and psychological support needs when their child is diagnosed with cancer and additional targeted support needs to be provided to support their physical well-being (for example the provision of nutritional meals) as well as their psychological well-being.
- Facilities and supports need to be provided in children's hospitals to assist mothers to care for newborns on the wards including the provision of lactation consultants.
- Grandparents need to be provided with support including psychological services that acknowledges their multifaceted roles in caring for multiple generations and the demands of having to alter family existing roles and adopt new responsibilities.
- Support within the community for grandparents who provide care for siblings including flexible working arrangements.
- Younger siblings experience their brother or sisters' cancer according to their cognitive and emotional skills and they need to be provided with psychological support that

acknowledges their needs and understandings including the use of toys to help them express their emotions.

- Increased delivery of information regarding childhood cancer by health care professionals (HCP) including explanations of treatment to reduce anxiety for all family members.
- A range of practical and psychological techniques should be employed, including virtual reality technology to assist families to manage the distress associated with painful procedures and treatments.
- HCPs should be educated via staff development that the death of children from cancer within the healthcare setting impacts not only the immediate family of that child but also has on other families in the childhood cancer community so that families can provide appropriate grief support.
- Information resources including infographic materials should be developed which incorporate advice from parents of children with cancer including advice for parents to seek both practical and psychological support and take care of their own well-being.
- Introduction of programs on the ward that help parents maintain a sense of normality including facilities for family meals.
- Paediatric healthcare systems should implement processes that enable the collection of data of the whole family including ethnicity, number of siblings, and parents work status/income. This would enable a better understanding of the composition of families and thus allow the delivery of more effective supports that target individual family members needs and would also assist in further research to explore the unmet needs of families.

Conclusion

These findings provide a comprehensive understanding of the impact of childhood cancer on families, emphasising the wide-ranging ramifications. The research showed that there are many complicated issues that arise when a child is diagnosed with cancer. It highlights the salient roles that gender, and societal expectations play in shaping familial experiences of childhood cancer and demonstrates the impact of changing workforce and generational demographics. It also shows that there is a paucity of support for all family members. Support needs to be provided that targets the specific psychosocial needs of different family members, adopting an ecological perspective to focus on both the individual child and the whole family. Care provided to family’s needs to consider each member's unique role within the family and society. In summary, all family members should be provided with support that acknowledges and provides for their individual needs and concerns.

Authors Note

This thesis was designed as a thesis by publication, and the chapters within the thesis have either been published or have been accepted and are waiting for final publication in peer reviewed journals. These papers are designed to be separate, stand-alone publications, which raises two issues. Firstly, there is unavoidable repetition between the chapters; for example, childhood cancer statistics, methodology, and ethical issues are repeated to some extent in each article. Some topics regarding issues such as ethics and saturation have been discussed in more detail in Chapter 3, as the limited word count of most publications prevents a thorough discussion of all aspects of the methodology. The second issue is that the collection of stand-alone publications may make the thesis disjointed. To correct this second issue, brief descriptions have been included to provide context, rationale and what it adds to current literature for each published article. In addition, the format and layout of each article varies due the publication requirements of each journal and in response to reviewers' feedback.

Positionality statement

Positionality is defined as the acknowledgement of the different life experiences and roles that the researcher brings to the research (Fenge et al., 2019). It explains how researchers make sense of how their experiences influence how they complete their research. It is crucial to acknowledge positionality as it highlights personal preconceptions that shape the research and how the data is interpreted. This statement is therefore an outline of my positionality and what lead me to this qualitative research project. Braun et al. (2022) use the analogy that qualitative research is like baking, in that strict adherence to the recipe is ostensibly necessary, but there is often more flexibility than might appear. They suggest experienced cooks (as with researchers) learn what rules must be followed and which can be adjusted. This edict applies to my research. Much of it was an iterative process where the research evolved in response to the interviews and data. As the research progressed, I learned to appreciate the experience I brought to it and developed confidence in my decisions, which I feel strengthened my findings. The following outlines my lived experiences and philosophical/educational background.

Lived experience.

Research has been described as an “adventure, a journey of exploration and discovery, down unfamiliar and perhaps rarely used pathways” (Braun & Clarke, 2022, p. xxvii). Everyone takes a different path to their research topic. For me, it was a path of tears and sadness, but one that ended with a passion and drive to work in childhood oncology. Until my daughter was diagnosed, childhood cancer was not something I thought much about. Cancer was a disease of adults, a disease that had taken several of my friends and my beloved mother just 12 months before. All of that changed in 2013 when, two days before Christmas, I received a call from the doctor that my 12-year-old daughter had cancer. At that moment, everything changed. Having to tell my daughter that she had cancer was not something I felt prepared for, and I had no idea what to say. How does one tell a child they have cancer? Especially one who had lost their beloved granny 12 months before to cancer. I knew that by telling her that her childhood as she knew it would be over. She would not have the normal experiences of being a teenager, feeling invincible and seeing a world of opportunities. Two days after Christmas, my daughter had her first PET scan, one of the scariest moments of my life. A few days later, we entered the oncology ward for her first appointment. Entering that world and seeing tiny children receiving chemotherapy is an image that changes you; it changed me, it changed my daughter.

I remember seeing a young baby with an NG tube and port, obviously very unwell. I will never forget the look on my daughter's face, a look of fear and sadness as she faced the realities of childhood cancer. Another moment that stands out is the first appointment with her oncologist. It was such a scary appointment, but with hindsight, we were so lucky to have the privilege to have an amazing oncologist. He spoke to my daughter like an adult, acknowledged our feelings and kindly explained everything. It highlighted that even the worst moment can be made more tolerable by healthcare professionals who listen and care. It also brought home to me that care provided to children with cancer needs to encompass far more than the medical. While this is obviously the priority, everything else, especially the psychosocial aspects, cannot be forgotten.

While this experience was awful on so many levels (too many to list), it also brought with it new friends, new experiences, and a newfound understanding of childhood disease. Having gone through this, and so shortly after having lost my mum to cancer, I felt I needed to make something positive come from it to make it make sense. My daughter took this experience, and motivated by her amazing oncologist, she set out to become a doctor. On the 19th of December 2023, ten years from diagnosis and at age 22, my daughter graduated with her medical degree as valedictorian, topping out her year. Sitting there watching her graduate, knowing what she has been through to get her there, was a fantastic experience. She aims to work in paediatrics, helping kids who are sick, as she understands so well what it is like to be a child in a hospital.

Having a child with cancer opened my eyes to the experiences of families and the toll it took on all family members: fathers, mothers, siblings, and grandparents. Childhood cancer ripples through the entire family, changing everything for each family member. It was my experience that began my research interest to examine the experiences of family members of children with cancer. It left me with many questions about the experiences I had observed while my daughter was being treated. As a single mother I also reflected on the different resources and services available to individual family members. The experience of a child diagnosed with cancer also highlighted the need to understand families' experiences better to improve care delivery. It was also my experience as a mother of a child with cancer that motivated me to employ a phenomenological methodology, as it allowed me to explore the meaning individual family members derived from their experiences of childhood cancer. Inspired by what I had experienced and observed and by the strength my daughter had shown, I began my PhD to explore the experiences of individual family members' experiences of childhood cancer hoping that the information I would find would enable me to improve the services for families of children with cancer.

I hoped that the knowledge acquired as an insider researcher would enable a more thorough appreciation of the complexities of participants' experiences and foster in-depth communications with participants during interviews. Of course, working as an inside researcher came with its challenges, as it often required me to revisit my own experience. This was particularly relevant when aspects of the participants' experiences mirrored my own. One of the most poignant moments was when a participant's child had been diagnosed at Christmas, given my daughter's Christmas diagnosis. To this day, Christmas is always a happy time, but also a time with many reminders of the most challenging point in my life. Discussing a diagnosis around Christmas time with the participant brought up so many memories, and in multiple ways, I had to reflect on my experiences and made a conscious attempt to be aware that these experiences may influence my interpretation.

There were also academic challenges working as an inside researcher. One aspect that arose during this research was balancing dual understandings of childhood cancer: one as an academic guided by ethical conventions around study, and one as a parent of a child with cancer. For example, the language required within the academic setting often differs from the language used by families. The emphasis within ethical academics is to use person-first language and not to define someone by their diagnosis. Within the context of this study, therefore, I described the child as the "child diagnosed with cancer". However, this goes against the common usage within the childhood oncology community that I belong to. Parents (and my friends) often refer to their child as my CK (cancer kid) when discussing their child and other siblings.

In many cases, the language used in the interviews had to be re-worded to adapt to the expectations of publications and academic standards. To many parents of children with cancer, describing their child as a 'cancer kid' is merely an apt description of the lives they are leading where the cancer becomes the focus, as it did for me during my daughter's treatment. As Braun and Clarke observe, language is essential, and how we describe things or groups impacts interpretations. My experiences with language shape my interpretation of meaning as an insider; however, academic protocols require the language to be amended to suit academic journal requirements (Braun & Clarke, 2022). The conflicting demands of academia and personnel experience were often challenging.

During this PhD, I also completed a parallel journey of learning about living with a chronic illness. Early in my research, I was diagnosed with an autoimmune muscle-wasting disease. This resulted in me becoming disabled and having to adjust my life to a world filled with medical procedures and hospitalisations (much of this thesis was written while in hospital). It also meant I had to learn to adjust to being a person with disabilities in a world that primarily caters to able-bodied people. Many of the aspects discussed by participants regarding their children were now my own experience. This was brought into stark focus for me when, midway through my research, I required a port (permanent vascular access device inserted in the large veins above the heart) to enable treatment to be delivered effectively. This device is commonly utilised in paediatric oncology and was frequently discussed by participants. Medications to treat my primary disease made me neutropenic, and hence, the world depicted by participants fearing infection became my personal on-going lived experience. This added a new dimension to my research and enabled another understanding of the world of childhood cancer families. While it has been a difficult and painful experience, it has helped me to empathise with families on a deeper level.

Political, educational, and philosophical background

Trainor and Graue (2014, p. 271) posit that "who we are, our identities, contribute to our positions and the vantage points from which we view a research problem". Therefore, researchers must reflect on their social, educational, and political positions to clearly explore their biases and philosophical perspectives (Braun & Clarke, 2022). It can be difficult to pinpoint precisely what shapes your view of the world and political positions, but a review of educational influences and family background can provide some insight. I've always enjoyed studying, and my mother supported my exploration of different educational goals. One of my first university degrees was in Communications Studies (including sociology units), which gave me a broad understanding of society and the world. In addition, my mother was a media teacher who has a single mother trained when I was a teenager, and we had many robust conversations about politics and society. The understanding gained from my education and my family has highlighted the impact of sociocultural influences on people's perceptions of their experiences. This influenced my selection of the ecological model within my research, as it incorporates the effects of macro-level cultural factors on the individual. I have also completed a History (Honours) degree focusing on primary sources, including research in the British Library. In many ways, the skills of analysing 19th-century documents (diaries & letters) to explore people's perceptions and meanings are comparable to the thematic analysis used to complete this research.

My history studies provided me with a theoretical perspective on the influence of gender and class on social experiences. Allen (2016) observes that feminist theory is an essential aspect of understanding families and their experiences. I consider myself both a feminist and a Socialist. I believe that traditional gender roles influence people's experiences. Moreover, despite changing expectations, the conventional roles of motherhood and fatherhood continue to impact family roles (Crotty, 1998). My Socialist foundations were formalised by a family with long traditions of working in the union movement, beginning with my great-grandfather, who took part in mining strikes in Wales. I was brought up with the knowledge that industrial action and social reform movements have given people the rights/conditions we enjoy today. My Socialist perspectives influenced my career decisions and research interests in examining the impact of social conditions on people's lives. I also have a family history of working in healthcare, education, and social reform. My mother was a massive influence on my educational endeavours and urged me to work to make the world a bit better than I found it. She was a teacher and told me and her students that if everyone aimed to make their little bit of the world just a little better, conditions would improve for everyone. She acquired this belief from her father (my grandfather), who had worked as a doctor, implementing NHS health reform in the United Kingdom in the mid-twentieth century.

This family background meant I had always had an interest in healthcare and the impact of social reform on broader populations. This interest led me to complete two post-graduate diplomas in public policy and healthcare, which provided me with an awareness of the complexities of the healthcare system, both offering insight and understanding that I utilised while trying to understand the services (or lack thereof) within the paediatric field. Working in healthcare research exploring the impact of childhood disease families seems to be an inevitable result of both a personal lived experience and educational and family trajectory.

CHAPTER 1 – Introduction

Chapter overview

This chapter provides information on prevalence rates of childhood cancer in Australia. The chapter will then go onto provide an overview of existing literature, broken down by the individual experiences of fathers, mothers, grandparents, and siblings. It will then provide a rationale for the study and will outline the research questions in detail.

Childhood cancer prevalence

In Australia, it is estimated that ~ 800 children will be diagnosed with cancer before the age of 15, with a diagnosis rate of 16 per 100,000 children (Health & Welfare, 2023). Cancer is characterised by the abnormal division of cells that can infiltrate nearby tissues and spread (Paul, 2020). Children under 4 years of age are most frequently affected (see Figure 1)

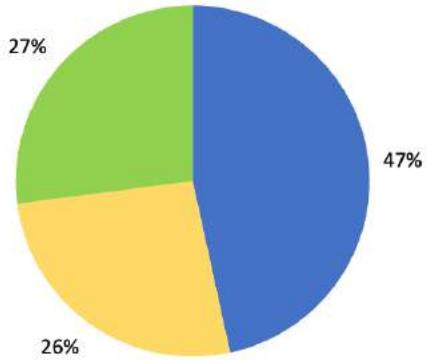

Figure 1. Incidence by age group 2011-2015, Australia (Youlden & Aitken, 2019)

The incidence of childhood cancer is higher among males compared to females, with 185 cases per million males and 163 cases per million females (Youlden et al., 2020). On average, Indigenous Australian children had an incidence rate of 152 per million children per year between 2011-2015, which is 13% lower than the incidence rate for non-Indigenous children (Youlden & Aitken, 2019). Leukaemia comprises the most significant proportion of childhood cancer cases, accounting for 35% of all instances, while central nervous system tumours constitute approximately 14% of childhood cancer cases (Health & Welfare, 2023). Cancer remains the leading cause of child death by disease in Australia, with an age-standardised mortality rate of 22 deaths per million children. Central nervous system tumours account for 39% of cancer-related deaths under age 15, with leukaemia accounting for 23% and neuroblastoma 11% (Youlden et al., 2020)

Between 1983 and 2015, the occurrence of childhood cancer in Australia rose by 34% (Youlden & Aitken, 2019). It is not known why incidence rates have increased so substantially, although it is theorised that changes in diagnostics and increased reporting may be factors (Youlden & Aitken, 2019). Youlden et al. (2020) conservatively estimated that the number of children diagnosed with cancer in Australia will increase by 40% within 20 years. As cancer incidence rates continue to rise, more children and their families will inevitably face a diagnosis of childhood cancer. This highlights the critical need for a more in-depth understanding of childhood cancer and its significant impact on families.

Despite increasing incidence rates, advancements in treatment protocols have led to a notable improvement in five-year survival rates. These survival rates have risen from 73% for children diagnosed between 1983 and 1993 to 85% for those diagnosed between 2004 and 2013 (Youlden & Aitken, 2019). The rigorous treatment protocols, consisting of a combination of chemotherapy, radiotherapy, surgery, stem cell transplants, and supplementary medications, frequently necessitate extended hospital stays and complicated care in the home (Wolfe-Christensen et al., 2010). These treatments also cause a range of distressing short-term side effects. These can include gastrointestinal symptoms, cognitive impairments, hair loss, infections, mood changes, weight loss, pain, and fatigue, which impact both the child and the family's quality of life (QOL) (Klassen et al., 2008). As more children are diagnosed with cancer and more children survive, there exists a rising demand to enhance the support given to both children and their families to reduce their distress.

While this thesis will focus on Australia, worldwide, it is estimated that 360,115 children aged under 15 years old will be diagnosed with cancer every year (Johnston et al., 2021). In Europe and North America, it is estimated that there are 178 cases per million (Johnston et al., 2021). Every year, more than 100,000 children and adolescents younger than 20 years of age will die from childhood cancer worldwide (Lupo & Spector, 2020). Whilst not all socio-geographic contexts will have similar experiences, there are likely to be commonalities underpinning familial experiences of childhood cancer; thus, a deeper examination of familial experiences of childhood cancer in Australia may yield understandings which can be applicable to other contexts and populations.

Literature overview

A child's cancer diagnosis causes a family crisis, triggering various stressors that affect every member of the family (Bally et al., 2014; Borrescio-Higa & Valdés, 2022; Kelada et al., 2019; Mckenzie & Curle, 2012; Molinaro & Fletcher, 2018). Alderfer et al. (2005) observed variations in how families respond to the child's diagnosis, contingent on many factors, including diagnosis, physical effects of treatment, and the child's treatment trajectory. Numerous studies have consistently shown that irrespective of the specific diagnosis and treatment plan, a child's cancer diagnosis profoundly affects the social and psychological well-being of all family members. (Ångström-Brännström et al., 2010; Bally et al., 2014; Castellano-Tejedor et al., 2017; Schepers et al., 2018).

Parents' experiences of childhood cancer

Young et al. (2002a) observe that many of the existing studies exploring parents' experiences of childhood cancer have focused on measuring psychopathology by measuring levels of distress and anxiety (Bemis et al., 2015; Kearney et al., 2015; Labrell et al., 2019). Such studies have consistently indicated that parents of children with cancer experience clinical symptoms of depression and anxiety alongside a diminished QOL (Aziza et al., 2019; Barrera et al., 2021; Klassen et al., 2008; Rensen et al., 2019; Sulkers et al., 2015; Warmerdam et al., 2019) . Researchers have adopted a range of methods to measure parents' psychological distress, including comparing rates of distress among parents of children with cancer to parents of children with other chronic diseases (Golfenshtein et al., 2015; Schepers et al., 2018; Sulkers et al., 2015). Scholars have also tracked parents’ distress across the disease trajectory; for example, Katz et al. (2018) found that at two months post-diagnosis, 74.3% of caregivers demonstrated clinical symptoms of depression. Regardless of the specific research approach, findings consistently indicate that the journey of a child receiving cancer treatment leads to significant challenges for caregivers, including increased rates of depression and anxiety.

Following on from the Diagnostic and Statistical Manual of Mental Disorders (DSM)'s 1994 expansion of the criteria for post-traumatic stress disorder (PTSD) to allow for parents to be diagnosed following their children receiving a life-threatening diagnosis, scholars began measuring rates of PTSD and post-traumatic stress symptoms (PTSS) amongst parents of children with cancer (Brown et al., 2003; Bruce, 2006; Clarke & Fletcher, 2003; Ljungman et al., 2015). The prevalence of parental PTSD lacks consensus, with rates ranging widely from 7% to 50% across different studies (Bruce, 2006; Dunn et al., 2012; Jurbergs et al., 2007; Stoppelbein et al., 2017). However, research on PTSS has yielded more consistent findings, with the majority of studies reporting that between 30% and 44% of parents exhibit clinical symptoms of PTSS (Alderfer et al., 2005; Axia et al., 2006; Dunn et al., 2012; Katz et al., 2018; Ljungman et al., 2015). Most studies have found that PTSS improves throughout the disease trajectory but can continue beyond the end of treatment (Ljungman et al., 2015). While research examining measures of psychological distress provide a useful metric on the impact of childhood cancer, it focuses on "maladjustment", which does not necessarily provide a complete understanding of what leads parents to feel distressed and may instead emphasise pathological constructs over lived experience (Young et al., 2002a).

Children with cancer requires their parents care and support both in the hospital and at home which leaves little time for their self-care. There is relative consensus within literature that a child's cancer diagnosis has significant detrimental impacts on parents' health (Aziza et al., 2019; Eyigor et al., 2011; James et al., 2002; Lewandowska, 2021; Wang et al., 2017). Klassen et al. (2008) reported that parents of children with cancer when compared to population norms reported poorer physical health in all domains. Research has also shown that many parents experience stress-related health conditions, including headaches, gastrointestinal issues, somatic issues, weight changes, appetite changes, and musculoskeletal problems (Aziza et al., 2019; Clarke et al., 2009; Lewandowska, 2021; Pai et al., 2007; Rensen et al., 2019; Wang et al., 2017). It has also been found that the stress and burden involved in caring for a child with cancer creates long-term health risks, such as cardiovascular health issues (Kazak et al., 2015; McLoone et al., 2013).

Childhood cancer also disrupts parents' sleep patterns, which has overall negative impacts on their well-being. McLoone et al. (2013) reported that parents of children with cancer who sleep on the ward have on average 5.7 hours of sleep, compared to seven hours for controls, and report waking up twice as many times as controls. This lack of sleep has detrimental impacts on physical health, including negatively affecting the immune system, worsening existing health conditions, and increasing anxiety and depression (McLoone et al., 2013; Meltzer., 2021; Steur et al., 2021).

Parenting a child diagnosed with cancer is complex, and research has demonstrated that parents experience stress when trying to balance roles and responsibilities (Al Omari et al., 2021; Compas et al., 2015; Kelada et al., 2019; Kerr et al., 2007; Long et al., 2015; Patterson et al., 2004; Silva-Rodrigues et al., 2016). Parents are part of a wide-ranging social system consisting of schools, social groups, workplaces, families, and friends. Childhood cancer changes interactions in these areas as their focus is directed inward toward caring for their child with cancer (Kahriman et al., 2020; Lewandowska, 2021; Lewandowska, 2021; Patterson et al., 2004). Managing caregiving responsibilities and the emotional burden can isolate parents from their social networks, making it difficult to maintain regular social interactions (Björk et al., 2005; Lewandowska, 2021; Pai et al., 2007).

Given the significant changes that childhood cancer creates, it is not surprising that it can impact the relationships between parents (Arruda-Colli et al., 2018; Compas et al., 2015; Lau et al., 2014; Lavee & Mey-Dan, 2003). Research has shown mixed results, with a 2018 study by Mader et al. (2020) finding that there are minimal impacts from childhood cancer on the relationship between parents, with no statistically significant difference in separation or divorce ten years after treatment completion compared with controls. This study, however, was completed in Denmark, where families are provided with thorough psychological support, which may reduce some of the negative consequences. In contrast, an American study by Wiener et al. (2016) found that parents reported that a childhood cancer diagnosis strained their relationship, particularly at the start and end of treatment, with most parents indicating they would value therapy. A systematic review of 14 articles by da Silva et al. (2010) found that childhood cancer had both negative and positive impacts on parental marital relationships, indicating that parents felt a closer bond to partners but that communication was often difficult. This demonstrates the complex and heterogeneous impacts childhood cancer can have on families and underscores the need for qualitative research which can capture nuanced lived experiences.

The impacts of childhood cancer are far-reaching, encompassing a full range of bio-psychosocial changes. Research seeking to understand these broad impacts has investigated the financial impact of childhood cancer, showing that families experience significant out-of-pocket expenses, including medical costs, medications, travel/accommodation expenses (for families residing in regional areas), parking fees, and incidentals related to living in the hospital, such as purchasing food and resources to support the child and siblings (Lau et al., 2014). However, there is a disparity in research findings concerning the precise effects on families. A review of 35 studies found that childhood cancer adversely impacted incomes (Roser et al., 2019). It identified that the most significant disruption occurs early in the diagnosis. In contrast, a study by Öhman et al. (2021) found that cancer in the long-term increased mothers' income. This study was, however, completed in Sweden, which provides people with comprehensive sickness benefits that include caring benefits, which means that when a child is diagnosed with cancer, parents are provided with employment protection so that they can be away from work and not lose their jobs.

Despite these points of heterogeneity, most studies emphasise the adverse impacts of childhood cancer, and it is essential to mention that experiences of childhood cancer vary depending on economic conditions and access to universal health care. In countries like the USA, there are different demands as health care often relies on employment, and the costs involved are very different to those in countries like Canada or Australia, where universal health care is available (Kelada et al., 2020). For example, in one study in America, participants reported losing homes, all financial savings, when employers did not provide appropriate leave when their child was diagnosed with cancer, creating major financial challenges for families (Neil-Urban & Jones, 2002). Although Australia's universal healthcare covers the majority of the healthcare costs, parents still need to manage numerous out of pocket expenses associated with a childhood cancer diagnosis rendering it a challenging experience for families (Kelada et al., 2020). To date, most literature explores the financial impact of a childhood cancer diagnosis within the context of the heteronormative nuclear family, focusing particularly on mothers and fathers. There is limited literature seeking to understand the impacts on extended family members.

Considerable research within the realm of childhood psycho-oncology has concentrated on identifying predictive factors that explain parental responses to childhood cancer (Barakat et al., 2021). Various aspects have been investigated, such as pre-diagnosis functioning, hardiness, parent educational levels, family income, resilience, and coping mechanisms (Compas et al., 2015; Salvador et al., 2019; Sulkers et al., 2015). A comprehensive review conducted by Sultan et al. (2015) analysed 43 studies, revealing several predictive factors, including inadequate individual resources, resilience levels, treatment type, and previous trauma. Further studies have aimed to identify behaviours which could bolster parental coping. For instance, a study by Hoekstra-Weebers et al. (2012) illustrated the significance of seeking social support in improving maternal distress levels in the short term. Whilst this approach can yield valuable clinical insights, it can be critiqued as adopting a paternalistic viewpoint, which foregrounds deficits in parental skills as a cause of distress. This may neglect to understand the broader social contexts in which parents sit. The development of interventions to empower families to cope relies on a holistic person-centred understanding of their experiences.

A growing body of literature has explored whether parents identify any positive outcomes from the cancer experience (Castellano-Tejedor et al., 2017; Gardner et al., 2017; Phipps, 2005; Willard et al., 2016). Molinaro and Fletcher (2018) found that while mothers highlighted difficulties, they also acknowledged some positives, including improved relationships with their partners and a new perspective on life, focusing on not stressing about small things. Similarly, Ljungman et al. (2016) asked parents about the positive aspects of their childhood cancer experience. They found that parents reported that it had resulted in some positive factors, such as having a new appreciation for life. Moreover, parents may find newfound strength and purpose in advocating for their child's well-being, contributing to a sense of empowerment amid adversity. Whilst these are valuable insights, the preponderance of literature exploring the positive aspects of childhood cancer may more broadly reflect a societal discomfort with constructs of childhood disease and mortality.

While understanding the impact of cancer on parents is inherently valuable, research has highlighted the impact of parental physical and psychological well-being on children's outcomes (Kearney et al., 2015; Wolfe-Christensen et al., 2010). Consequently, research has been undertaken to explore whether a relationship exists between parental distress levels and childhood distress. Robinson et al. (2007) reported that parental functioning affects children's psychological processing of their diagnosis. Similarly, other studies have demonstrated a correlation in children with cancer between parental psychological disorders and the child's QOL, depression, anxiety, and PTSS (Bakula et al., 2019; Clawson et al., 2013; Okado et al., 2014). Scholars have therefore suggested that it is essential to understand the impact of cancer on families, not only for its intrinsic benefit to family members, but also for the potential to improve outcomes for children themselves (Woodgate, 2006).

Gender differences in parental responses to childhood cancer

Research highlights distinct differences in how fathers and mothers navigate the challenges of cancer, underscoring societal norms that often position mothers as the primary caregivers during their child's treatment (Clarke et al., 2009; Gibbins et al., 2012; Hoekstra-Weebers et al., 2012; Lewandowska, 2021; Murphy et al., 2008; Pai et al., 2007; Yeh, 2002). Katz et al. (2018) reported that 86% of families identified the mother as the primary caregiver. Numerous studies reveal disparities in anxiety, depression, and stress levels, with mothers consistently experiencing higher rates of psychological distress and posttraumatic stress symptoms throughout the disease trajectory (Al-Gamal et al., 2019; Pai et al., 2007; Rensen et al., 2019; Robinson et al., 2007; Vrijmoet-Wiersma et al., 2008). For example, Ljungman et al. (2015) found that five years after the end of treatment, 19% of mothers had PTSD compared to 8% of fathers. This discrepancy may stem from mothers' prolonged stays in the hospital, exposing them to more traumatic experiences while observing their children undergoing painful and unpleasant procedures (Vrijmoet-Wiersma et al., 2008). In addition to higher levels of stress and anxiety, studies also indicate that mothers of children with cancer face a diminished QOL (Clarke et al., 2009).

Research indicates that mothers often face substantial disruptions in their lives following a child's cancer diagnosis (McEvoy & Creaner, 2022). One key aspect of this disruption is observed in work, where mothers are more inclined than fathers to give up or significantly reduce their paid employment (Al Omari et al., 2021; Kelada et al., 2020). Notably, there are cultural variations, exemplified by Japanese research revealing that up to 80% of mothers permanently withdraw from the workforce, while in Canada, this figure stands at 20% (Miedema et al., 2008; Okado et al., 2014). Despite these differences, research consistently underscores that most mothers undergo such disruptions with significant long term financial implications.

While fathers generally exhibit lower levels of psychological distress and less work disruption, they face distinct stressors, including balancing work-family commitments (Chesler & Parry, 2001; McGrath & Huff, 2003; Nicholas et al., 2009; Robinson et al., 2019). Fathers typically continue their employment to support their families financially (Brody & Simmons, 2007; Kelada et al., 2020; Robinson et al., 2019). This can create stress for fathers, who report feeling torn between fulfilling their financial responsibilities and attending to the needs of their child with cancer (Higham & Davies, 2013; McGrath & Huff, 2003, 2003; Nicholas et al., 2009). Some research has, however, reported that fathers also find that work provides a distraction from childhood cancer (McGrath & Huff, 2003).

Fathers often perceive exclusion from various aspects of caregiving and report that they feel relegated to a secondary role compared to mothers, where mothers make decisions regarding treatment in a phenomenon termed "maternal gatekeeping" (Hill et al., 2009). Within the hospital setting, fathers want to be involved in medical and treatment decisions but often encounter restrictions that mothers and health care professionals (HCPs) impose on their day-to-day participation in care (Bailey-Pearce et al., 2018; Hill et al., 2009; Hovey, 2005). Additionally, research by Reis et al. (2017) revealed that fathers of children with chronic illnesses in hospital found the hospital environment unwelcoming, with some sensing judgment from healthcare professionals regarding their ability to care for their children HCPs. The literature suggests that such feelings of being marginalised may contribute to the trauma fathers experience (Bailey-Pearce et al., 2018; Chesler & Parry, 2001; Yogman et al., 2016).

Given the typical role that mothers undertake as primary caregiver, studies examining the impacts of childhood cancer on parents have disproportionately relied on reporting from mothers as proxies for the family (Al-Gamal et al., 2019; Dunn et al., 2012; Jurbergs et al., 2007; Kazak et al., 2005). Numerous studies use the term "parents or caregivers" when the sample predominantly consists of mothers (see Appendix B for examples of demographics of studies reporting on parents/carers). This tendency to use mothers as proxies for families' experiences has two methodological issues. Firstly, it fails to capture fathers' individual experiences and overshadows mothers' experiences, reducing the ability to capture each parent's unique perspective. There is a need for more research that captures parents' individual experiences, focusing on how cultural gender roles and responsibilities impact their responses to their child's cancer diagnosis. There is a body of research exploring mothers' experiences; however, these studies have often examined particular cancers such as leukemia or brain cancer or have focused on mothers' perception of the impact on their child and ability to cope (Al Omari et al., 2021; Chen et al., 2015; Compas et al., 2015; Labrell et al., 2019; Molinaro & Fletcher, 2018). While some studies, notably Young et al. (2002) and McEvoy and Creaner (2022), have examined mothers' roles and identities, there are few studies which specifically examine mothers' experiences. There is a need for more qualitative studies that specifically delve into the personal narratives of mothers and acknowledge them as individuals.

There is currently a dearth of research explicitly exploring the father's individual experience of childhood cancer (Archibald et al., 2021; Bailey-Pearce et al., 2018). Many studies exploring fathers also have small sample sizes; for example, several studies have sample sizes of fewer than five participants (Hill et al., 2009; McGrath, 2001; McGrath & Huff, 2003, 2003). While these studies provide a foundation, there is a need for a more extensive study. One methodological issue that may explain this lack of fathers is that some of the previous research has recruited fathers through hospital/clinic attendance, which in many countries with limited income support for families only captures those fathers who are providing caregiving to the child with cancer; as such, it may fail to gather information from fathers who are unable to step into caregiving role within the hospital due to work commitments (Brody & Simmons, 2007). Most research has not targeted fathers specifically, which may deny fathers the opportunity to express their thoughts and views.

Moreover, most of the published qualitative literature explicitly examining fathers' experiences of having a child with cancer dates back over a decade. In the preceding decade, there has been a shift in societal attitudes to parenting with fathers taking a more hand on role (Banchefsky & Park, 2016; Borgkvist et al., 2020; Jones et al., 2021; Reis et al., 2017). As well as needing more research on fathers' experiences, there is also a need to understand the impact of changing societal expectations on fathers' experiences. Parents are products of their social environment and are affected by gender roles and expectations that are determined by culture.

Currently, limited research examines these issues (Reis et al., 2017). There is a need for more studies which incorporate fathers' perspectives, and which seek to understand how fathers experience childhood cancer.

Siblings' experiences of childhood cancer

Childhood cancer creates a shift in roles and family dynamics, significantly altering 'normal life' for siblings (Nolbris et al., 2007; Prchal & Landolt, 2012). Scholars have noted that the needs of siblings are often ignored in the stress and upheaval caused by the cancer diagnosis (Prchal et al., 2012; Van Schoors et al., 2021). While there is variation, most research demonstrates that siblings have reduced psychological well-being. Numerous factors can cause psychological distress for siblings, including having to witness their brother/sister undergoing treatment or experiencing side effects, being away from parents, and changing routines (Prchal & Landolt, 2012). A study by Kaplan et al. (2013) reported that 60% of siblings reported moderate to severe PTSS, 34% met the criteria for PTSD, and 75% demonstrated co-morbid symptoms of anxiety and depression. This study also found that 77% reported that they thought the child with cancer life was in danger after the diagnosis, and 48% reported feeling intense fear and helplessness. Similarly, Alderfer et al. (2003) found that PTSS was a significant concern for siblings, with 49% having mild levels of PTSS and 32% indicating moderate to severe levels.

The siblings of children with cancer also encounter substantial effects across other life domains, including academically and socially (Woodgate, 2006). In one study, 30% of parents indicated that the siblings' education was negatively affected by childhood cancer (McLoone et al., 2013). This can include increased absenteeism rates and deterioration in school grades.

Increased rates of absenteeism may exacerbate psychological distress for siblings as the school has also been shown to provide some benefit as an escape and distraction from the stress of cancer (Prchal & Landolt, 2012; Salmon & Bryant, 2002). Thus, siblings of children with cancer are required to adapt to a new way of life, and they experience many losses that can be overlooked in the trauma of dealing with a life-threatening illness (Houtzager et al., 2004; Sloper, 2000).

Siblings must manage a complex emotional landscape, dealing with fear, uncertainty, guilt, anxiety, and confusion (Long et al., 2015; Van Schoors et al., 2019; Wilkins & Woodgate, 2005). Research has shown that siblings have expressed that they feel overlooked and jealous of that the child with cancer received more attention (O'Shea et al., 2012; Porteous et al., 2019; Van Schoors et al., 2019; Weiner & Woodley, 2018). Siblings describe feeling envious of the gifts that the brother/sister with cancer receives; however, despite reporting resentment, they also describe understanding why their brother/sister receives additional gifts (Prchal & Landolt, 2012; Tasker & Stonebridge, 2016). Some research, however, has reported that siblings did not express any significant resentment towards siblings or parents, likely reflecting the heterogeneity within siblings as a group (Van Schoors et al., 2019).

Another aspect emphasised by research is the disturbance and stress induced by care arrangements. Due to the parents need to stay with the child with cancer in the hospital, siblings are often cared for by relatives (usually grandparents) or friends (Deavin et al., 2018; Long et al., 2018; Van Schoors et al., 2019). Siblings experience emotional and physical separation from their parents and report missing a sense of family cohesion (Long et al., 2018). Given the stress and anxiety that siblings experience, a growing body of research has emphasised the need for siblings to be provided with more support to manage the changes wrought by childhood cancer (Woodgate, 2006).

While childhood cancer research in psycho-oncology has made significant progress in exploring siblings' experiences, there is still a need for further research. One methodological issue with many of the studies on siblings is that they have gathered data from parents, child/parent dyads, and/or staff (Alderfer & Hodges, 2010; Ballard, 2004; Pariseau et al., 2020; von Essen & Enskär, 2003). Some of these studies where observations are obtained from parents may minimise impacts, as parents are focused on the child with cancer, which means they may not be able to fully grasp the impact on siblings (Ballard, 2004). These methods may mask the individual experiences of siblings, as siblings may be reluctant to express their emotions for fear of causing negative emotions for parents (Yi, 2009). This may overlook the nuanced experiences of siblings. Future research should prioritise including siblings' voices directly, fostering a more comprehensive understanding of their perspectives.

In addition, most of the existing literature focuses on older siblings (above 12 years) and young adults, and experiences are often described retrospectively (D'Urso et al., 2017; Long et al., 2018; Porteous et al., 2019; Prchal & Landolt, 2012; Van Schoors et al., 2019; Weiner & Woodley, 2018). This may be due to the perception that older children can better articulate and recall their experiences (Prchal & Landolt, 2012). Other studies have focused on a wide range of ages, including children, adolescents, and adults (Kobayashi et al., 2015; Pariseau et al., 2020)). For example, Woodgate (2006) study sample ranged in age from 6-21 years. Developmentally, the difference between a 6-year-old and a 21-year-old is vast. Pre-adolescents are less self-aware and reflective than adolescents (Blakemore & Choudhury, 2006). Thus, their responses to childhood cancer may vary considerably. In addition, older teenagers tend to rely more on friends and social networks than younger children. One drawback of much research is the failure to account for variations in siblings' experiences based on their age or developmental stage. Similarly, younger children may require higher levels of parental engagement and support to facilitate developmental progression, whereas adolescence is marked by increasing independence. Long et al. (2015) and Weiner and Woodley (2018) argue that developing a detailed understanding of younger siblings will enable targeted, effective support strategies to be developed for siblings.

Grandparents’ experiences of childhood cancer

The experiences of grandparents in the context of childhood cancer are multifaceted, encompassing practical, psychological, and social dimensions. Research on the impact of childhood cancer on grandparents has found mixed results. Findler (2014) found no difference in QOL between grandparents of children with cancer and grandparents in the control group. In contrast, Australian research conducted by Wakefield et al. (2016) and Wakefield et al. (2014) revealed that grandparents exhibit diminished QOL, and poorer physical health compared to control groups. Additionally, Wakefield et al. (2016) demonstrated that grandparents had elevated levels of depression, anger, and anxiety compared with controls. They also found that grandmothers experience poorer QOL than grandfathers, as do those living in urban areas and grandparents who are retired or unemployed (Wakefield et al., 2016). Further research by Kelada et al. (2019) found that grandparents reported lower levels of family functioning than a control group. As such, while there is variance, most of the research does appear to demonstrate a reduction in the psychosocial well-being of grandparents of children with cancer.

When a child is diagnosed with cancer, grandparents often also take on new roles to care for their other grandchildren, including taking on parental aspects such as school runs, after-school activities, and sometimes moving in with the family to provide care for siblings (Wakefield et al., 2014). The financial and logistical aspects of supporting a family through childhood cancer, such as travel to medical appointments or providing full-time childcare for siblings (often stepping into parental roles), can create additional challenges for grandparents (Backhouse & Graham, 2012; Moules et al., 2012). For grandparents, having a grandchild diagnosed with cancer entails not only the practical challenges and emotional toll of seeing their grandchild experiencing a life-threatening illness, but also having to process the emotions of seeing their adult children experiencing trauma and fearing the death of their child (Moules et al., 2012; Tatterton & Walshe, 2019). Grandparents often express that they worry about their grandchild with cancer and their adult children, a situation which has often been described as "double grief" (Hall, 2004; Moules et al., 2012). Research reports that grandparents find this burden or worry about two generations to cause distress and anxiety (Wakefield et al., 2014). This dynamic also entails navigating difficult boundaries, with grandparents often not wanting to distress their adult children by expressing their emotions, nor wanting to encroach on their adult child’s parenting role (Wakefield et al., 2014).

Research exploring grandparents’ experiences is limited and has generally focused on measurements of psychological distress or examination of communication issues and care of siblings. More research is needed to explore the dynamics of support networks involving grandparents (Findler, 2014). Studies still need to explore how their roles in family employment and social networks are changed by experience, particularly in the context of changing expectations of ageing and demographics. Understanding how grandparents engage with extended family, friends, and community resources can inform the development of interventions that strengthen the broader support systems available to grandparents during the childhood cancer journey. There is also a need for a more in-depth exploration of specific emotions experienced by grandparents.

Study rationale

While there is a growing body of research exploring the impact of childhood cancer on families, there is a need for further qualitative research to explore their lived experiences (Castellano-Tejedor et al., 2017; Gibbins et al., 2012). This understanding of lived experiences is crucial in identifying unaddressed needs of individual family members and directing further research. On a more philosophical level, developing a deeper understanding of lived experiences allows us to give a voice to individuals' whose experiences may not be well-understood academically and can inform and direct HCP's approaches to families of children with cancer. Qualitative research recognises the importance of individuals' experiences. Its objective is to gain insight into how individuals derive meaning from their experiences, facilitating the development of practices and policies tailored to meet their needs (Braun & Clarke, 2021; Denzin & Lincoln, 2013; Leavy, 2017). Many of the existing qualitative studies have used small sample sizes. While small sample sizes are standard in qualitative research, samples of five or fewer people may result in data that does not have depth or information power and may not provide a full exploration of family members' experiences (Guest et al., 2020; Hennink et al., 2017; Mason, 2010; Saunders et al., 2018).

In addition, many qualitative studies on childhood cancer have focused on dyads or have recruited families via hospital databases, meaning the mother, as the primary caregiver, acts as a proxy for the family. Looking at the family's experience as a whole from the mother's perspective may overlook the complexities of different roles, needs, and contexts of individual family members. There is a need for research whose recruitment strategy is diverse, accessing potential participants via different methods to enable all family members to be included.

It is also vital to understand the contextual issues surrounding family members of children with cancer. Every family member impacted by childhood cancer will experience the diagnosis of cancer differently depending on a whole range of factors. For example, Chesler and Parry (2001) observed that gender roles influence coping mechanisms and roles within the family, including tasks performed in caring for children. Previous life experiences, including ill health and previous stressors, will also influence how family members experience childhood cancer. These influences can be conceptualised as occurring across all levels of the ecological system. Kelada et al. (2019) argued that there was a need for research to explore the impact on the broader family system and the potential for support to be expanded, underscoring the significance of ecological impacts. There have also been significant changes in social roles and responsibilities in recent decades, and more research is required to explore whether these changes have impacted individual family members' experiences (Baxter et al., 2015; Buchanan & Rotkirch, 2018; Coles et al., 2018; Moussa, 2019).

This study will provide an understanding of individual family members' experiences and facilitate the exploration and development of supports which are targeted to individual family members' experiences. By gaining a richer understanding of the ways in which socio-cultural, community and personal factors shape experiences of childhood cancer, this research seeks to inform healthcare systems, researchers and clinicians in better serving the needs of families of children with cancer (Robinson et al., 2007).

Overall research question

What is the lived experience of individual family members (fathers, mothers, siblings, grandparents) of a child diagnosed with cancer?

Specific research questions

- What is the impact of a child’s diagnosis of cancer on family members?
- How do socio-cultural roles and expectations impact individual family members' experiences of childhood cancer?

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CHAPTER 2 – Methodology

Chapter overview

This chapter provides an in-depth discussion of research paradigms, elucidating the epistemological stance and philosophical assumptions that shape my view of the world. An overview of the theoretical perspective underpinning this study is also presented, followed by a detailed exposition of the methodology employed in my study. The chapter will then provide a discussion of inside researchers. It will conclude with an overview of methods used within this study.

Research paradigms

A research paradigm explains the researcher's assumptions or ways of thinking about the world (Levers, 2013). Numerous scholars emphasise that researchers must make clear their assumptions regarding the nature of society and reality to understand their research approach (Braun & Clarke, 2022; Crotty, 1998; Holden & Lynch, 2004). Two main paradigms guide research: positivism and interpretivism (Crotty, 1998; Levers, 2013).

Positivism theory proposes that reality is set and independent of human perception (Crotty, 1998). The purpose of research in the positivist paradigm is to explain phenomena based on specific 'infallible' knowledge (Park et al., 2020; Pham, 2018; Rehman & Alharthi, 2016). Positivism is less focused on the individual and how they make meaning, but instead looks at the big picture, including societal structures and how people behave in those societal structures (Crotty, 1998; Levers, 2013; Pham, 2018). It focuses on 'observable reality', which can be measured using statistics and measurements, enabling the development of set rules to determine causal relationships (Alharahsheh & Pius, 2020). This approach is thus more commonly used in quantitative research as it focuses on gathering data that can explain human behaviour (Crotty, 1998).

An alternative paradigm is interpretivism, which proposes that there are many different realities and different truths that are socially constructed and change according to an individual’s perceptions (Goldkuhl, 2012; Khan, 2014; Petty et al., 2012). Interpretivism suggests that social phenomena should be considered from different perspectives since individuals interpret and make meaning differently depending on their contexts (Alharahsheh & Pius, 2020; Crotty, 1998; Levers, 2013). This approach had its foundations in German idealism. It was developed in its current use by Max Weber, who argued that researchers should focus on social actions and how people make meaning from social interactions (Goldkuhl, 2012; Putnam & Banghart, 2017). In this paradigm, reality is influenced by individuals’ pre-existing knowledge and cultural, historical, and economic circumstances (Goldkuhl, 2012). Using this approach, researchers seek to explore how individuals interpret and make meaning from their experiences, focusing on people's beliefs and feelings (Alharahsheh & Pius, 2020; Levers, 2013). Qualitative research is the most common approach within the interpretivist paradigm and allows researchers to gather information based on individuals’ experiences (Braun & Clarke, 2022).

My research was positioned within the interpretive paradigm, aiming to delve into how family members of children with cancer construct meaning and interpret their experiences, influenced by their unique individual backgrounds. This approach aligned with the interpretive paradigm, considering that there is no pre-determined way of experiencing childhood cancer and that each person's history, culture, past experiences, education, and family structure will impact how they respond, make meaning of, and react to childhood cancer. It also explored how the social constructions of motherhood and fatherhood and the social roles parents adopt can influence their experience of childhood cancer. Furthermore, it included an exploration of how people's feelings about death and their life trajectories play a role in how they interpret the experience of childhood cancer.

Epistemology

Epistemology is the theory of knowledge and gives a philosophical basis for considering what knowledge is possible and what counts as knowledge (Alharahsheh & Pius, 2020; Bahri Khomami et al., 2021; Crotty, 1998, p. 3; Krauss, 2005; Lee, 2012). Crotty (1998, p. 3) describes it as “a way of understanding and explaining how I know what I know” Researchers need to explain their beliefs regarding the theory of knowledge as it enables others to understand the researcher's work in the context of their stated belief system (Alharahsheh & Pius, 2020; Bahri Khomami et al., 2021; Krauss, 2005). The nature of knowing has evolved throughout history, and theories have developed in accordance with peoples' belief systems (Raskin, 2002). The three leading epistemological schools of thought are objectivism, subjectivism, and constructivism (Galbin, 2014; Rønnow-Rasmussen, 2003; Wilson, 2000).

Objectivism

Objectivism adopts a positivist approach and postulates that there is one 'true' reality, and it is the job of researchers to seek out this 'truth' that is independent of the researcher (Krauss, 2005; Lee, 2012). This philosophical system was proposed by Ayn Rand, an American writer whose theories were popularised through her novels and promoted the idea of individualism and political structures that prioritise laissez-faire capitalism (Sciabarra, 2003). Objectivism holds that there is one reality independent of anyone perceiving it. This means that regardless of whether or not someone perceives something, it still exists (Clegg, 2017; Levers, 2013). Objectivism does not analyse contextual factors, and knowledge is universal as objects hold an essence separate from human activity or beliefs (Levers, 2013). It often seeks to find a ‘causal explanation’ that can explain a phenomenon and involves developing a hypothesis that can either be proven or disproven (Holden & Lynch, 2004).

Subjectivism

Subjectivism is the philosophical theory that no truth exists outside of one's own experience (Crotty, 1998). This theory posits that truth is subjective and depends on the subject's experience; what is valid for one person may not be true for another (Holden & Lynch, 2004; Raskin, 2020; Rønnow-Rasmussen, 2003). Universal knowledge is impossible as it is influenced by the observer (Levers, 2013). This approach focuses on the meaning of the phenomenon rather than simply measuring and proving reasons for the experiences (Applebaum, 2012; Holden & Lynch, 2004). In this epistemological approach, researchers cannot distance themselves from the subject matter as their beliefs will influence how they interpret their reality (Levers, 2013).

Constructionism

Constructionism postulates that knowledge and meaning are not there to be discovered but constructed (Crotty, 1998; Galbin, 2014). Constructivism has emerged as a leading theory of learning since the 1970s and arose in contrast to behaviourist theories, which were seen not to include the person's role in the learning process (Brody & Simmons, 2007; Lee, 2012; Liu & Matthews, 2005). There are varying definitions of constructionism, and as Raskin (2002) notes, researchers have yet to achieve explicit agreement on the specific definition of constructivism. However, some overriding principles are shared. In the constructionist approach, there is no one 'correct viewpoint', and people construct their meaning differently depending on their view of the world (Lee, 2012; Liu & Matthews, 2005). It also adopts a relativist ontology that multiple realities depend on experiences (Amineh & Asl, 2015). Constructionism includes considering the 'contextual factors' when exploring phenomena (Appleton & King, 2002). This paradigm also asserts that people's understandings are formed through their cultural norms, values, and interactions with other people (Braun & Clarke, 2022). As Crotty observes, "without culture, we could not function … we depend on culture to direct our behaviour and organise our experience" (Crotty, 1998, p. 53). Our culture gives us rules and ways of seeing the world, and from a constructionist viewpoint, meaning cannot be described as objective (Appleton & King, 2002; Lee, 2012). In this paradigm, there are many different and sometimes contradictory accounts of the same experience, and all are equally valid (Crotty, 1998).

I used constructivism in my study as it aligned with my research aim to explore how people make meaning of their lived experience of childhood cancer and how social constructs influenced their experiences (Creswell & Poth, 2016; Labonte & Robertson, 1996; Thomas et al., 2014). Meaning is created by those who interpret it and the phenomena itself (Levers, 2013). Krauss (2005) asserts that the desire to make meaning is one of the most fundamental aspects of human social setting and that humans will strive to make sense of the world and interpret their reality. In this way, meaning provides a way to understand events and phenomena. This concept of meaning-making was fundamental to my research as I sought to understand how family members made meaning from the experience of childhood cancer. This assumption of constructionism also has an understanding that researchers ‘produce’ rather than ‘reveal’ evidence (Braun & Clarke, 2022). In this way, the researchers' past experiences and meanings will influence data analysis and the meanings found in the data. My research adopts this stance with an awareness that my experiences and perceptions as a mother of a child who was diagnosed with cancer will influence the interpretation of the data.

Phenomenology

Phenomenology is a method where researchers aim to explore the meaning of people’s “lived experience” (Chamberlain, 2009; Neubauer et al., 2019). Gallagher and Francesconi (2012) describe phenomenology as a process that does not ask people why they think the way they do, but about what it was like to experience the phenomenon, allowing them to provide descriptions of their feelings and impressions. It focuses on people's perceptions and gains insights into people's narratives (Alhazmi & Kaufmann, 2022; Starks & Trinidad, 2007). There have been varying schools of thought regarding the methods used in phenomenology research, and each of the philosophers developed their interpretations regarding how it should be conducted (Alhazmi & Kaufmann, 2022; Neubauer et al., 2019).

Husserl is considered the founder of modern phenomenology, first describing this approach at the turn of the 20th century (Chamberlain, 2009; Sloan & Bowe, 2014). Husserl refuted positivism and the belief that there was a known reality, postulating instead that reality was dependent on people's consciousness, arguing that how people conceptualise an object defines the meaning of that object (Neubauer et al., 2019). He argued that people should focus on the “inner evidence” (Neubauer et al., 2019). Phenomenology is thus seen as “the study of consciousness” (Crotty, 1998; Neubauer et al., 2019). The Husserl phenomenology aims to reveal the essence of a phenomenon. To do this, Husserl argued that researchers should suspend their experiences and perceptions and approach phenomena as naive researchers. He proposed 'bracketing' and setting aside one's thoughts, perceptions, and biases. Researchers should be aware of their preconceived ideas and understandings and reflect on how that may influence any interpretation (Crotty, 1998; Starks & Trinidad, 2007).

Heidegger aligned with Husserl in rejecting positivism but diverged as it focused on people as 'knowers' of their experiences, emphasising how people interact with the world (Sloan & Bowe, 2014). He posited that people’s subjective experiences are intertwined with social, political, and cultural contexts (Neubauer et al., 2019). Heidegger's approach to phenomenology is generally described as hermeneutic or interpretive phenomenology (Neubauer et al., 2019). This hermeneutic phenomenology posits that people always understand their place in the world, even if they are not necessarily consciously aware of it at all times (Neubauer et al., 2019). According to this approach, people cannot experience life without being impacted by their own previous experiences, background, and understandings (Neubauer et al., 2019).

The concept of “nature of being in the world” was used by Heidegger to describe how people interact with the world, this was termed as the 'lifeworld' (Neubauer et al., 2019). He argued that the Husserl approach could describe experiences but could not truly explore what it “means” to be a person (Neubauer et al., 2019). Hermeneutic phenomenology involves the researcher interpreting the accounts provided by participants concerning their place within the world (Neubauer et al., 2019). He also suggested that the individual parts shape people's understanding of the whole and how they relate to it, arguing that everything is interrelated

(Dowling, 2004). Heidegger saw this as a circular, iterative process of evolving understanding, which he described as the ‘hermeneutic circle’ (Dowling, 2004; Neubauer et al., 2019; Whitehead, 2004).

A critical difference between Heidegger's and Husserl's phenomenology is how they frame the role of the researcher (Neubauer et al., 2019). Heidegger's hermeneutic phenomenology suggests that researchers cannot bracket off their perceptions and that these add value to the research (Neubauer et al., 2019). Requiring the researcher to separate their beliefs and understandings contradicts the fundamental philosophy of hermeneutic phenomenology, which suggests that people (researchers included) interpret their experiences based on their understandings (Neubauer et al., 2019). In hermeneutic phenomenology, researchers must acknowledge their own bias and understanding of their ‘lifeworld’ and consider how this may impact their research (Dowling, 2004; Rennie, 2012). In contrast to Husserl, Heidegger saw these past experiences as beneficial to research, arguing that they give the researcher insight into the phenomenon (Neubauer et al., 2019)

Hermeneutic phenomenology focuses on understanding what it is like to experience a particular phenomenon but also aims to interpret how people make meaning from their experiences (Neubauer et al., 2019). My research adopted a hermeneutic phenomenological approach as this approach aligned with the objectives of this study to understand people's different points of view and understand what it was like to experience childhood cancer (Dew, 2007). The aim was to move beyond just describing the experiences to explore how people make meaning from their experiences as influenced by their place in the world, including cultural and social aspects (Neubauer et al., 2019). The approach is also consistent with the ecology systems theory, as it focuses on the individuals and how they interact, emphasising people's lived experiences and feelings/understandings (Sundler et al., 2019).

Theoretical framework: Ecological systems theory

My study was guided by ecological systems theory, which informed my choices regarding methods and approaches (Crotty, 1998). This theory is a helpful heuristic for understanding the wide-reaching impact of childhood cancer as it seeks to account for both the context and complexity of individual experiences and the interplay between different layers of society (Bronfenbrenner, 1979). The ecological systems theory was developed by American psychologist Urie Bronfenbrenner in 1979 and sought to explain how children are influenced by the different environmental systems in which they are embedded (Ettekal & Mahoney, 2017). Bronfenbrenner was critical of previous childhood development theories, arguing that they saw children in isolation and did not factor in the interrelated aspects that influenced their development (Neal & Neal, 2013). Ecological systems theory has become one of the most influential theories in developmental psychology and has been used to understand education and socialisation in various settings (Härkönen, 2007). Ecological systems theory describes how individuals are nested within an extensive complex social system (see Figure 2).

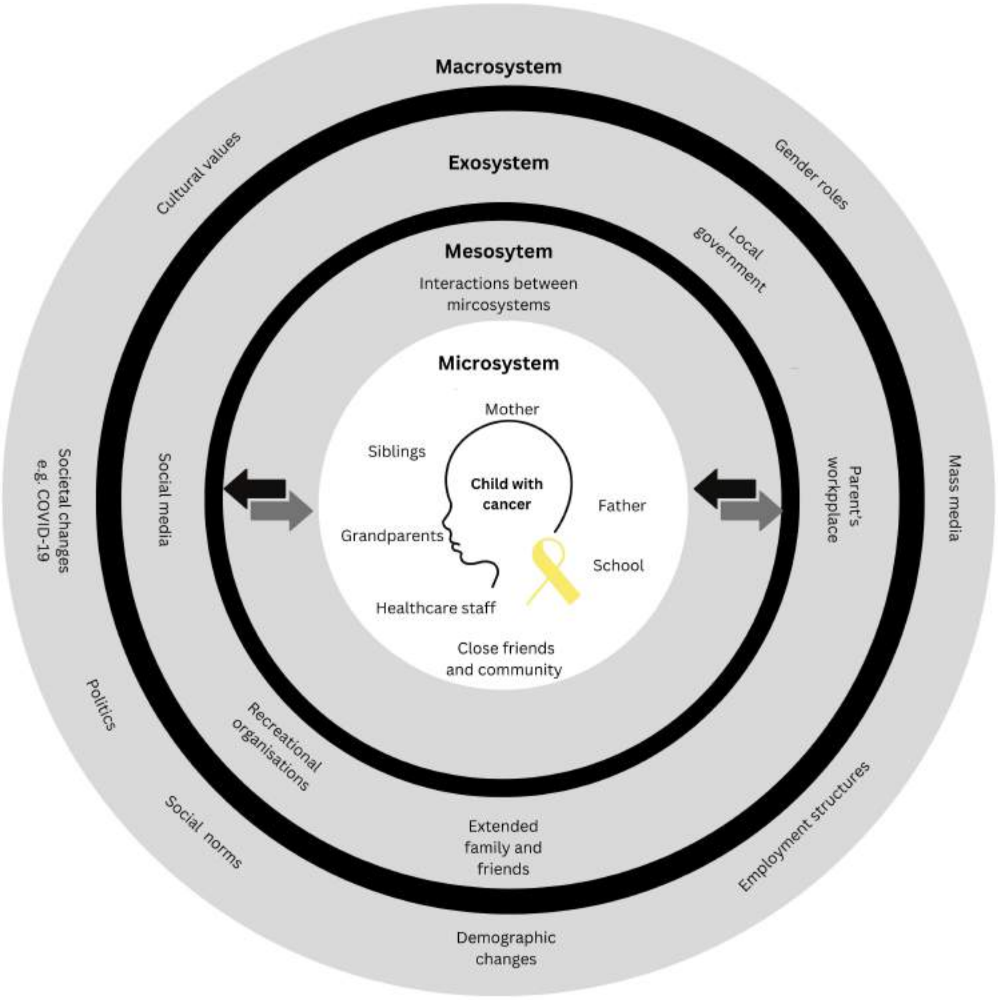

Figure 2. Adaption of Bronfenbrenner (1979)'s Ecological Systems Model: Childhood oncology

Within this model, there are five nested levels. The innermost level, most proximal to the child, is the *microsystem,* consisting of those aspects of the system that the child interacts with directly; for example, family, schools, and friends (Bronfenbrenner, 1979). The microsystem influences the child most, and what happens in one microsystem impacts other microsystems. Relationships are also bidirectional, as a child's behaviour can influence the child, and the child can influence people in their microsystem (Onwuegbuzie et al., 2013). Moving outward, the next level in the ecological model is the *mesosystem*. This describes the interactions between different elements of the microsystem, for example, between parents and HCP. These interactions impact each other. For example, being teased at school may influence how a child responds to their family (Onwuegbuzie et al., 2013). The *exosystem* refers to subsystems that are not directly connected to the child but impact the child indirectly, for example, work and government. The outermost level, most distal to the child, is the *macrosystem*, which consists of the overarching cultural and political attitudes and values; for example, beliefs around gender (Bronfenbrenner, 1979). The macrosystem's influences include societal roles and expectations and influence behaviour within the ecological model. The macrosystem influences all the other aspects of the ecological model, and these belief systems and policies change and evolve (Onwuegbuzie et al., 2013).

The ecological system theory explains how people influence and are influenced by their environment (Härkönen, 2007). Ecological systems theory posits that a person's well-being depends on interrelated and complex factors within the social system within which they sit (Bronfenbrenner, 1979). This theory posits that it is not just individual personalities and traits that influence well-being and emphasises the interconnectedness of people and that the well-being of one person affects others (Murrell, 1973). It therefore provides a conceptual framework for articulating the necessity to look at the context surrounding the child with a cancer diagnosis and highlights the need for any analysis of childhood cancer to include an examination of those who are proximal to the child, such as parents, but also the extended family and broader community. Ecological systems theory is useful when examining social issues as it allows for a conceptual understanding that all individuals sit within many social systems simultaneously, and each social system each has its own set of expectations, roles, and demands (Darling, 2007;

Murrell, 1973; Murrell & Norris, 1983). This approach also emphasises the interconnections between the different layers and how these change in different contexts. In recent decades, community psychologists have therefore argued that any strategy or interventions used to support people must be tailored to individual contexts that focus on why people behave in specific ways (Burke et al., 2009; Murrell & Norris, 1983; Neal & Neal, 2013; Stokols, 1996).

Ecological systems theory also proposes that social systems are not static and change in response to events (Darling, 2007). This awareness provides an ability to consider the changes that occur within the social system when a child has cancer. HCP, typically considered relatively distal to the child, become more proximal for the family and the child (Ringer et al, 2013; Wilford et al., 2019). Ecological systems theory also provides a vehicle for looking at the individual in a broader context. It highlights that all individuals are nested within broader macro-cultural systems, which shape values and beliefs and influence how individuals perceive their experiences (Darling, 2007). The context, for example, often shapes these beliefs for those with a child diagnosed with cancer; media representations of children with cancer take on a heightened salience. In contrast, those without the experience of childhood cancer tacitly consume this media without questioning representations. Using the ecological systems theory, Kazak (2001) argued that there is a need to conceptualise and manage childhood cancer at a broader level, understanding that the child with cancer sits within a more comprehensive framework, which incorporates multiple interacting subsystems. Murrell and Norris (1983) has contended that the interdependence between systems means it is difficult to 'improve' conditions in one system when facing stresses in another**.** Therefore, if we aim to improve the psychosocial outcomes of families of children diagnosed with cancer, it is crucial to examine and understand all aspects of the ecological model, its levels, and the interactions between these levels.

Qualitative research

The qualitative approach allows people the opportunity to describe their thoughts and perceptions and for researchers to develop an understanding of individual lived experiences (Bleiker et al., 2019). Hannum et al. (2019, p. 523) contends that the qualitative approach prioritises the perspectives, experiences, and languages used by those most intimately familiar with a particular phenomenon. Qualitative research commonly uses the social constructivism paradigm to explore how people make meanings from their experiences and includes contextual factors (Lee, 2012). I felt that this method would enable me to explore the meanings individual family members made from their lived experiences of a child with cancer. My experience as an inside researcher has shown me that many families did not feel 'heard'. The choice of qualitatively asking family members what it was like, thus giving them a voice, resonated as a method that would be suitable for this research.

Qualitative research as we know it today arose out of the Chicago School of Sociology in the 1930s (Gilgun, 2015). Some of the basic tenets of qualitative study date back to early 19th-century historical research that explored the experiences of different cultures, gathering various data on people's views (Denzin, 2017). This was often grounded, however, in white colonial, patriarchal frameworks, and in these contexts, the voice of the researcher was often prioritised over those being studied (Clark, 2004; Manning, 2003). The focus in the 1970s moved towards psychosocial aspects, and the 1980s saw a prioritising of disenfranchised feminist, ‘queer’, and culturally diverse communities (Otani, 2020). Early criticisms of qualitative research contended that qualitative dependency on researcher analysis and its subjective nature meant that its results were not reliable or valid (Krauss, 2005). The core differences in qualitative and quantitative research are not simply just the methods used to gather data, but are founded in fundamental philosophical differences in the construction of reality (Krauss, 2005). Quantitative researchers argue that the best way to understand a phenomenon is to measure and quantify it in a scientific approach, with the theoretical assumption that there is one reality. Qualitative researchers argue that this only measures one small aspect of reality and ignores the context of the phenomenon (Krauss, 2005). Proponents of qualitative research argue that qualitative research allows for the development of a deeper understanding of particular phenomena as it provides an opportunity to identify problems and give voice to personal narratives (Denzin, 2017; Dew, 2007; Hannum et al., 2019; Rabionet, 2011).

One of the benefits of the qualitative approach is that it enables the exploration of social systems and practices (Koch et al., 2014). It focuses on elucidating rather than quantifying different perspectives; thus, it can be used to explore people's and communities' needs and has the potential to impact social policy (Denzin, 2017; Sundler et al., 2019). Within the healthcare context, it can help identify the need for improvements in service delivery. Healthcare and oncology have adopted qualitative techniques since the 1950s to improve service delivery and practice (Hannum et al., 2019; Rodriguez & Smith, 2018). The qualitative method can provide helpful information on various healthcare issues, including well-being, beliefs, social support, and details about the patient experience (Granek & Nakash, 2016; Hannum et al., 2019). It can reveal problems with service delivery that may need to be evident in quantitative research. As Hannum et al. (2019) observe, it is essential in healthcare research to specify what is relevant to practice and what can be used to inform improved service delivery. My research focused on strategies and measures that could be implemented within the paediatric oncology setting to improve service delivery for family members based on their needs. Thus, this research method was considered suitable for this study as it allowed people to describe their perceptions of services and supports provided (Bleiker et al., 2019).

A range of empirical approaches are used in qualitative research to collect data, such as case studies, interviews, cultural texts, and observational and historical accounts (Johnson et al., 2020**).** Interviewing is one of the most common methods to gather information and involves the researcher, either one-on-one or in focus groups, asking a series of questions about a particular group's lived experience. Cypress (2018, p. 303) describes an interview as "a conversation with a purpose”. Denzin and Lincoln (1994) describe it as “the art of asking and listening”. My study employed semi-structured, one-on-one interviews to gather data, allowing participants to discuss sensitive issues. Semi-structured interviews involve the development of a document with interview questions tailored to meet the objective of the research question (Dempsey et al., 2016; Gysels et al., 2008; Knox & Burkard, 2009). A carefully developed interview guide is an essential element of completing qualitative research and provides the foundation for the interview; however, it is also a flexible document that allows for modifications as the research progresses (Kallio et al., 2016). One of the benefits of qualitative research is that it is iterative, responding to the specific research question and circumstances with the ability to modify the research framework according to the information gathered (Hannum et al., 2019).

In my study, I developed the interview guides based on previous research and discussions with consumer representatives, stakeholders, and the supervisory team, and changes were made as the research progressed (see Appendix C). One of the benefits that I found in using a flexible interview guide is that it provided a structure that enabled essential topics to be covered, but also allowed topics to be explored naturally in response to participants’ answers (Kallio et al., 2016). This method of interviewing also assisted me in developing a good rapport with participants, as it allowed the interview to be conducted as a structured conversation that felt natural while still achieving the research objectives. Prompts were also used to provide more information and allow further exploration of topics under discussion (Dempsey et al., 2016). This flexible approach allowed issues such as the COVID-19 pandemic to be explored more deeply.

Analytical approach

This research used reflexive thematic analysis (TA) as its analytical approach. Reflexive thematic analysis was proposed by Braun and Clarke (2006) and aimed to create an easy-to-follow method to increase TA accessibility (Braun & Clarke, 2021). TA belongs to the phenomenological research tradition, which focuses on participants' "lived experience" and how they make meaning from those experiences (Braun & Clarke, 2021). Braun et al. (2022, p. 434) describe that reflexive TA is about "telling a story and making an argument" My research set out to ‘tell the stories' of families of children with cancer, allowing participants to explain in detail what it felt like for them and how it impacted their lives. TA can be used with either a deductive or inductive methodology. The deductive approach involves approaching the data with an existing hypothesis that is tested (Azungah, 2018; Hyde, 2000). The inductive approach involves deriving meaning and creating data themes without preconceptions (Azungah, 2018). My research adopted an inductive approach, exploring the data without any existing hypothesis, allowing themes to be developed from the data (Koch et al., 2014). This enabled me to explore issues as they arose; for example, the issue of mothers who were pregnant when their children were diagnosed with cancer. There was no preconceived aim to explore this issue, but it arose in the initial interviews and TA, and then research decisions were made to explore this topic in more depth.

Braun and Clarke outlined six steps for TA data (Braun & Clarke, 2006). The first step involves getting familiar with the data by reading through the transcripts and taking notes on initial impressions regarding participants' comments/answers. This step also served as an opportunity to re-listen to the interviews after transcription and make any necessary amendments following transcription. The second stage of TA involves systematic data coding; after reading transcripts, codes were developed using a manual paper-based process with codes attached in the margins. The third stage involves generating the themes from data and codes. The fourth stage consists of developing and reviewing early themes. A thematic map was developed to represent findings to assist the fourth phase graphically. In the fifth phase, all authors reviewed and revised themes to ensure unnecessary themes were excluded and that sufficient data to support each theme was present; in addition, names were given to each theme. The final stage involved the themes being written up into a report. To reduce the possibility of identification of participants care was taken during the analysis and writing of results not to provide quotes with multiple identifying factors, for example, gender of the child with age and diagnosis as these details could combined could identify participants to those in the childhood cancer community.

While Braun and Clarke set out steps in their original research in 2006, in later articles, Braun and Clarke (2021) argue that TA needs to remain flexible, fluid, and contextual (Braun & Clarke, 2019). They suggest that remaining fixed on a ‘set' way of doing TA denies the very purpose of TA. It is not one set approach but consists of multiple approaches, all with a similar basic philosophy to “capture patterns of data” (Braun & Clarke, 2021). Reflexive TA is what is termed "Big Q"-qualitative, which acknowledges the researcher's subjective analysis as a 'resource'. (Braun & Clarke, 2021). Many researchers refer to themes ‘emerging' from data; however, Braun and Clarke are reluctant to use the term 'emerged themes' as it implies that the themes exist without researchers' input (Braun & Clarke, 2021). Braun and Clarke (2021) describe TA as an active process and prefer the terms 'generating' or 'developing'. They emphasise that the researcher's observations and experiences should be considered a 'resource' for the researcher rather than a risk to credibility. Themes are developed through interpretation by the researcher and require the researcher to continually reflect on their viewpoints (Braun & Clarke, 2021). In my research, I aimed to complete TA concurrently with the interviews and data collection. This enabled themes to be explored continuously, allowing me to reflect on the information being explored within the interviews.

TA is an active process that requires spending time with the data. It requires the researcher to reflect, question, and think about the information, often going back after setting aside some time to gain new observations and reflect on how personal experiences may shape analysis (Braun & Clarke, 2021). It is a time-consuming and complicated process that requires thought and time. Good coding benefits from distance, which is often achieved by taking a break from the data (Braun & Clarke, 2022). Setting aside data and then coming back to it for review was a fundamental component of my research process and allowed for different perspectives to be explored. Having completed previous qualitative research, I aimed in this research to allow at least two to three weeks after completion of the first round of TA to set the results aside which provided space to reflect and think about the data. This process proved beneficial as a second review often demonstrated a more precise and in-depth set of themes. A few weeks after completion of the first TA, I also re-read all transcripts in detail, making additional notes, and recording any impressions, and then compared this to the initial TA. This ensured that I had adequately explored all the meanings and perspectives within the transcripts.

Rigour and quality

Questions have risen in qualitative research about how to ensure methodological rigour (Creswell, 2007; Hannum et al., 2019). Koch (2014) asserts that rigour is tied to how a researcher's epistemology informs their interpretive framework (Koch et al., 2014).The constructivist approach suggests that there is no one reality, and thus, trying to 'establish validity' and set out to measure set constructs to demonstrate quality becomes difficult (Krauss, 2005). This has created debate within the field of qualitative research in trying to develop a method to demonstrate that the study has been completed with rigour. Academics argued that there needed to be criteria that paralleled those used in quantitative principles of internal and external validity, reliability, and dependability to enable some measure of rigour (Anney, 2014). To address this, in 1981, Lincoln and Guba developed the criteria of creditability, transferability, dependability, and confirmability (Hannum et al., 2019). Credibility refers to the confidence that the research correctly represents the participant's data (Anney, 2014; Stahl & King, 2020). Transferability relates to providing enough information so that readers can decide if the results apply to other situations (Anney, 2014; Shenton, 2004). Dependability confirms that study is detailed enough that the work could be repeated. Confirmability demonstrates that the results are based on research information, not the researcher's bias (Johnson et al., 2020; Shenton, 2004).

To ensure that this research had overall quality and rigour, I followed Tong et al. (2007)'s Consolidated Criteria for Reporting Qualitative Research (see Appendix D). This is a 32-item checklist that is designed to help researchers report aspects of their research in three domains: research team and reflexivity, study design, data analysis, and reporting. The research team and reflexivity domain relate to clearly stipulating the researcher's positionality and experience. Domain two, study design, relates to the theoretical framework and includes elements such as theory, sample size and data collection. The data analysis and findings domain include how data were coded, the generation of themes, and participant checking.

Several mechanisms can be used to ensure credibility in qualitative research. One of the main methods is triangulation, which incorporates several elements. Firstly, it requires using different data sources and having researchers review the data (Cypress, 2017; Shenton, 2004; Stahl & King, 2020). In this study, we aimed to gather data from multiple sites around Australia, both urban and regional, to capture different perspectives. To ensure investigator triangulation, the study supervisory team reviewed data (Korstjens & Moser, 2018). Member checking was a strategy employed to ensure credibility and dependability (Cypress, 2017). After analysis, preliminary themes were sent to a selection of participants to review to ensure they adequately represented data. Dependability was also ensured by completing thorough audit notes and recordings of the reasons for decisions made during the research process (Stahl & King, 2020). Reflexive journaling was also completed to explore my thoughts and biases and how these may have influenced the research (Anney, 2014; Johnson et al., 2020).

One of the principal ways rigour can be shown is when a researcher is transparent and open about their research and explains why they completed it in a particular way (Davies & Dodd; 2002). In my research, I was conscious of reviewing and discussing why I made the decisions regarding the methodology and process of the research and to discuss with the supervisory team and within my writing. In addition, I also had numerous conversations with stakeholders within the childhood cancer community to discuss my research methodology. I feel that this was vital to ensure that the study-maintained rigour and openness.

Saturation

There is no clear definitive number of interviews that need to be done in qualitative research to obtain sufficient data (Vasileiou et al., 2018). It is necessary for the research process and for ethics committees and academic review panels to decide and explain the sample size (Guest et al., 2020). A very large sample can raise questions regarding how much time was spent on interviewing and if that was necessary to explore the research question (Kindsiko & Poltimäe, 2019). In contrast, a small sample size can make it difficult to decide if enough information has been obtained. Kindsiko and Poltimäe (2019) suggest that there is often a tendency to revert to quantitative explanations of having sample sizes described as being more legitimate if they are larger rather than explaining if the sample size was adequate to meets the needs of the research. The intention of qualitative research is to explore topics in more detail, and this often requires a smaller sample size than in quantitative research. Unlike quantitative research, there is no clear guidelines that can be used to determine how many participants should be recruited.

In order to address this issue of sample size in qualitative research, in 1967, Glaser and Straus described the concept of ‘theoretical saturation’: the point at which no new theoretical insights are developed (Guest et al., 2020; Saunders et al., 2018). It thus focuses less on repetition of data but on the theory being developed (Vasileiou et al., 2018). The concept of theoretical saturation is still used within grounded theory as an explanation of when to cease collection of data when an adequate sample size has been achieved (Guest et al., 2020; Johnson et al., 2020; Saunders et al., 2018; Vasileiou et al., 2018).

Recently, academics have suggested that the focus be less on an adequate sample size and number of participants, and more on depth of data, a term described as ‘information power’: this is the point where interviews provide no new information that assists in addressing the research question (Guest et al., 2020; Malterud et al., 2016). Information power theory posits that as the richness of information within a sample increases, the necessity for a larger sample sizes decreases (Malterud et al., 2016). Saunders et al. (2018) observe that saturation is often seen as an event or point that can be determined. However, saturation can also be seen as a process where there is always the possibility for new information to arise, but at which point the collection of more data does not add significant value (Saunders et al., 2018). When enough in-depth information is achieved, the researcher hears the same information or comment repeatedly (Guest et al., 2020; Malterud et al., 2016). According to the concept of information power, saturation occurs when interviews yield minimal or no new information relevant to the research question. Saturation is reached, and no further interviews need to be conducted (Guest et al., 2020). Further data is sometimes collected to 'confirm' that saturation had been achieved or to ensure that a diverse sample is obtained (Saunders et al., 2018).

In this study, I focused on ensuring that I had in-depth data, and when it appeared that the same information was being heard with little new understanding being added, I considered ceasing recruitment. In some studies, I continued when there was a focus on seeking specific participants (for example, mothers who were pregnant).

Inside researchers

Braun and Clarke (2022) observed that reflecting on how one's viewpoints and experiences will influence the research and analysis is essential. As an inside researcher, I was conscious to continually reflect on how this might shape the research. Inside researcher refers to a researcher who conducts research within communities "of which they are also members"

(Asselin, 2003). The inside researcher has two roles: researcher and community member (Greene, 2014). In contrast, an outside researcher's perspective is a naive status with no personal experience of the community/experience they are researching. Qualitative researchers are inevitably influenced by our own experiences and beliefs about the world (Greene, 2014). Being an inside researcher will also impact how we understand the research topic. As researchers, our understanding is grounded in our social constructs, and insider/outsider perspectives influence how we conduct research (Finefter-Rosenbluh, 2017).

An insider research status can impact the research in multiple ways. One of the benefits of inside researcher status is that it can make it easier to recruit participants, as the researcher has access to methods of recruitment that are not open to outsiders. Being an inside researcher provides access to a community that is often difficult to access, given the trauma and the phenomenon of voyeurism. Many groups are reluctant to open up to the general community and vigorously guard their privacy (Dempsey et al., 2016). Inside research status allows for easier access to gatekeepers, such as closed social media sites (Dempsey et al., 2016). Being an inside researcher also means participants may feel more comfortable explaining their feelings if they feel the researcher understands their experiences and has an existing understanding (Fenge et al., 2019; Finefter-Rosenbluh, 2017). This enables insider researchers to collect rich data, mainly when dealing with sensitive topics. In addition, knowledge of the community can enable the study to be framed around existing needs and reduce feelings of distress around any upsetting aspects of the community (particularly relevant to research in healthcare settings).

While there are benefits that are also possible areas of concern. One of these is that the inside researcher may feel that they know the community and understand all the issues, which may lead to the project being framed and data interpreted around these understandings. Another negative of inside researcher status that while they may have understanding, they may not know those with different experiences. In addition, Finefter-Rosenbluh (2017) suggests that inside researchers may have problems 'detaching' from their experiences, which may impact their analysis and interpretation. Foster (2009) suggests that there is a tendency to assume that outsiders will be more objective, and insiders will be less likely to be able to bracket their feelings and experiences. To address this, it is argued that researchers must go beyond their perceptions and understandings, be aware of their own experiences, and try to recruit those who have experienced different contexts (Finefter-Rosenbluh, 2017).

Researchers have noted that insider status creates the possibility of bias as the topic is examined through a particular lens (Greene, 2014). This status, however, can also create advantages as it provides an understanding of the community (Bonner & Tolhurst, 2002). I approached this research with an understanding that my experiences influence my understanding. In addition, the inside researcher status requires the ability to explore one's own experiences and manage any emotions that may arise, including an awareness of the need for self-care strategies to manage any emotional aspects (Leavy, 2017). Within the qualitative approach, researchers must consider and acknowledge their position and how this may influence their data analysis (Finefter-Rosenbluh, 2017).

Chavez contends that inside researchers can be either total—those who share 'profound experiences' with the community—or ‘partial insiders', who share some aspect of the community (Chavez, 2007). The idea that it is a dichotomy, where the researcher is either an insider or an outsider, is untrue. Rather, it is a continuum (Greene, 2014). It is also not 'definitive', but rather a flexible and changing status depending on the researcher's experiences (Finefter-Rosenbluh, 2017). As Foster (2009) observes, one shared experience does not mean there is complete understanding, and there is the possibility of a plurality of experiences. These differences need to be respected with an understanding that there is the possibility for the insider and outsider status to be blurred depending on the experiences of both the researcher and participant (Foster, 2009).

I come to this research with an insider perspective. However, as Breen (2007) observes, the dichotomy of insider-outsider may reduce the complexities of research, and it may be more advisable to consider it along a continuum. My daughter is now an adult and no longer in active treatment, and thus, I no longer sit strictly within the active community. Additionally, the perspectives I sought in this study were outside my personal experiences, such as those of fathers and grandparents. While there are many similarities in my experiences of childhood cancer and knowledge of the oncology ward is similar, I am not a father, grandparent, or sibling of a child with cancer, and each of these groups brings individual experiences with their unique perspectives.

At first, I was not sure how to maintain the line of professionalism and the distance that is required as an academic, and I was not sure how to discuss my own experiences of childhood cancer with participants. However, with confidence, I learnt that there were benefits in talking about my experiences briefly. I believe sharing my experiences allowed them to trust me and meant they felt more comfortable providing in-depth explanations of their thoughts and feelings that they may not have otherwise shared.

Ethical considerations

Health research inevitably means conducting research with communities that may be considered vulnerable. It often requires discussing sensitive topics that may cause some distress to the participants and researcher (Dempsey et al., 2016). Researchers are required to uphold the theories of beneficence and non-maleficence—or doing good and avoiding harm. There is no one clear definition of what is a ‘sensitive topic’, but largely it is considered a topic that is emotional and likely to create feelings of distress (Dempsey et al., 2016). It is important, therefore, for researchers to consider how best discuss sensitive topics and how to reduce the impact on participants and researchers. Given the sensitive nature of this study and the topics being discussed, it was anticipated that some participants could find the discussions difficult. Being comfortable sitting with emotional distress and not changing the subject when topics become difficult is often a valuable skill to elicit rich data.

Sometimes negative feelings occur for researchers in relation to causing distress for participants (Dempsey et al., 2016). In addition, asking questions about negative experiences can be an emotional experience for researchers (Fenge et al., 2019). Fenge et al. (2019) observes that researchers may experience various feelings including anger, frustration, guilt, and a sense of helplessness when dealing with emotional data. Dempsey et al (2016) suggests researchers being aware of the ‘power’ given to them to discuss sensitive issues and seek support to manage the feelings that arise from dealing with vulnerable populations. To manage the emotions involved in discussing these topics, I used a reflexive diary to record and explore emotions. Another strategy employed was connecting with various stakeholders in the community (other family members of children with cancer) who provided an opportunity to discuss my experiences and emotions to enable insight into how I was feeling.

Consumer involvement

Consumers can provide valuable first-hand knowledge and experience which can be used to inform practice and service delivery (Hall et al., 2018). First theorised in the 1970s, consumer involvement had grown in popularity in recent decades and is now a fundamental part of research across the world (Milley et al., 2021) There is a need for lay people who have experienced the topic under research to be involved so it remains grounded in their experiences (Milley et al., 2021). There is an increasing changing power relationships between consumers and researchers with a focus on doing research with rather than about people (Ward et al., 2010). Consumer involvement also increases the ability to recruit participants and then disseminate findings (Ward et al., 2010). It is important to avoid tokenism, where consumers are consulted on only a surface level to prevent this I ensured that consumers were involved in all levels of the research process (Hall et al., 2018). Consumer involvement has multiple benefits, including development of a study that reflects community needs, improved ethics, and reducing burden on participants (Milley et al., 2021). The following strategies were used to ensure consumer involvement:

Table 1.

Consumer involvement in the research process

- ⇒ Initial consultation with stakeholders (including family members of children diagnosed with cancer) from not-for-profit organisations that support families of children with cancer and with HCP.
- ⇒ Consultation with university-based consumer advisor.

⇒ Recruitment of formal consumer representatives either via notices placed on social media or direct recommendation from support organisations.

⇒ Discussion on study design and process with consumer representatives.

⇒ Study documentation reviewed by consumer representatives.

⇒ Review of initial themes with participants and consumer representatives

⇒ On-going discussions with stakeholders re: initial findings and themes.

⇒ Stakeholder organisations/groups support with dissemination of findings to community members.

Translating research into practice

Curtis et al. (2017) observes that there can often be a long lag in translating medical research into practice within the health care system (Curtis et al., 2017). One of the factors that increases the translation of research into practice within health care settings is to ensure that the process of translation is included during the research process (Curtis et al., 2017). There is also a need to be aware of the complexities and plan for how changes will be implemented (Curtis et al., 2017). During the research process it was considered important to try both disseminate and then translate the research into practice. After the initial data collection, a process was developed to disseminate the results to raise awareness and thus increase potential for translation of the findings into practice. This has involved multiple media stories regarding the research, which aimed to promote awareness of childhood cancer. Meetings have also been completed with HCP within local health care services and with government representatives including the state governments Minister for Health. I have also presented the findings of the study on pregnant mothers at several seminars at the state maternity hospital and have had discussions with midwifery services about the potential to improve services for mothers who are pregnant when their child has cancer. Discussions have also commenced with the state children's hospital and stakeholder organisations to introduce peer support services for fathers. It is hoped that these various strategies will enable the translation of these findings into long-term changes that benefit families of children diagnosed with cancer.

Methods

The following section provides details on methods used within this study to address the research question. The research was conducted in accordance with all guidelines as stipulated in the National Statement on Ethical Conduct in Humans. Ethical approval was provided by Curtin University in March 2020 (see Appendix E; NHRMC, 2018). The researcher held a current Working with Children card, an Australian government system to regulate child-related service providers.

Two childhood cancer organisations provided letters of support prior to the ethics application. Consumer representatives were selected by consultation with the community and word of mouth. Individual consumer representatives included mothers, fathers, grandparents, and one adult sibling. An additional representative who had been pregnant when their child had cancer was included in this study after the decision was made to examine this issue. These representatives reviewed documents, including the interview guide, and provided feedback throughout the research process. Once the process and documentation were complete and ethics approved, recruitment began in March 2022. The eligibility criteria were developed to include a broad range of families (see Table 2).

Table 2.

Participant eligibility criteria

Population	Eligibility Criteria
Parents and grandparents	• They had a child/grandchild 17 years or younger who was currently receiving or had completed treatment within the previous 15 months for curative intent. • Able to converse in English. • For the purpose of this study, stepparents or those in de-facto relationships, and adults performing parental or grandparent caregiving roles, including non-biological parents/grandparents, were included in the study.
Siblings	• Siblings aged 6-15 years of a child diagnosed with cancer who was currently receiving or ceased treatment within the previous 15 months. • Siblings were defined as biological siblings, stepsiblings, and children/adolescents in the same household. • Able to converse in English.

*Exclusion criteria**:** Family members of children receiving palliative care were not eligible for participation.*

Recruitment

To ensure that the study did not just reflect the limited experiences of one hospital, the study sample for this research was drawn from across Australia. This decision was made to gather a broad perspective of families' experiences. Participants were initially recruited by convenience sampling of participants who were accessible through childhood oncology groups (Leavy, 2017). To achieve this, the researcher approached various Australian organisations and hospital-based social media groups in other states to request assistance with recruiting. The inside researcher status facilitated recruitment. The initial contact provided a brief overview of the study and outlined the researcher's personal experience as a mother of a child with cancer. Organisations responded positively, and all expressed appreciation that research was being undertaken. All organisations and groups approached agreed to distribute recruitment flyers and/or place notices on their websites to assist with recruiting (see Appendix F). Organisations were then provided with relevant information, allowing me to join Facebook groups or place notices on my behalf. Throughout the research process, they were contacted at the commencement of each research project phase (fathers, mothers, grandparents, and siblings). On several occasions, they also reposted the notices to encourage participation.

Flyers outlining study details were also provided to several not-for-profit organisations in various states who distributed flyers to family members and on social media. Snowball sampling was also used to seek out participants who met the research purpose and to ensure a good cross-representation of different perspectives (Johnson et al., 2020). As my study does not aim to explore family dynamics and interactions, all participants were recruited individually to capture their experiences. However, in some cases, multiple members of the same family participated.

Recruitment was staggered, with recruitment of fathers commencing first. This was slow initially (complicated by early COVID-19 changes which limited face-to-face distribution of flyers), and thus, after three weeks, the decision was made to begin recruitment of mothers. These were done is separate recruitment processes targeting individual groups. Grandparents were then recruited, and once that process was complete, siblings were recruited in the last phase. All recruitment strategies requested that participants contact the researcher via email or a research-specific phone number. Participants and siblings' parents were contacted directly to organise interview times and locations.

Before the interview, all participants were given a study participant information sheet and a consent form (see Appendices G, H). They were also given a demographic questionnaire which collected data for each participant, including family composition; data on the child's age, gender, diagnosis, and treatment, and when diagnosed; siblings' age; and gender, education levels, and work status of parents and grandparents (see Appendix I).

Procedure

Interviews with participants were conducted in a venue of the participants' choosing or via Microsoft Teams/Zoom. This included participants' homes, workplaces, and the family rooms of local childhood cancer organisations. Informed consent was obtained from participants in addition to verbal assent from children. A flip chart consent tool was developed for children with simple language and emojis that outlined the study process (see Appendix J). For children taking part in online interviews, the flip chart consent tool was emailed to parents who were requested to go through it with them. Children were interviewed at their homes or via Microsoft Teams/Zoom. However, these interviews occurred separately to parents, and parents were not present in the room at the time of the interview to enable children to speak freely. Interviews were digitally recorded, with consent for the recording gained from participants prior to the interview. At the commencement of the interview, all participants were provided a brief overview of the study and asked if they understood the study information.

At the end of each interview, all participants were allowed to add further comments and ask questions. Participants were also informed that they could be provided with copies of the final research paper after the study and that the results of the project may be presented at conferences or published. They were also given a $20AUD gift card and a list of support services to contact if talking about their experiences had caused distress (see Appendix K).

At the completion of analysis, several adult participants from each group (mothers, fathers, and grandparents) were randomly selected and asked to provide feedback on overall themes. Of the nineteen participants contacted, thirteen responded and indicated that themes were an accurate reflection of their experiences. For the siblings' study, initial themes were discussed with consumer representatives (fathers and mothers) and stakeholder organisations.

Managing distress

To address any issues regarding sensitivity, the researcher was mindful to ensure that if participants expressed distress, they were given options to cease/pause the interview, and all participants were given support services contact details. Despite the sensitive nature of the topics being discussed, no participants opted to cease the interview. Judgement of distress relies on personal judgement and responsiveness to cues; for example, the judgment that the participant has had a dramatic change from giving detailed responses to giving short one-word responses with no outward signs of emotion, which can indicate a negative reaction. In these circumstances, I checked in with the participant regarding their well-being and provided them with the option of stopping or offered water if in-person. When questioned about their level of distress and if they were comfortable, most participants were very keen to continue with the interview, and many expressed gratitude for the opportunity to discuss the difficult experiences. Several opted to take a short break (1-2 minutes) to drink water and gather their thoughts.

When participants had appeared distressed during the interview, the researcher sent a follow-up email after the interview to inquire about their well-being and prompt them to contact relevant support services as per the information provided at the time of the interview. All participants received relevant contact details for mental health support services, including in-person and online/telephone services. Parents were provided with child-specific service details and suggested to contact them if needed (see Appendix K). These were provided in paper form or emailed to participants after the interview.

In addition, the well-being of family members involved in the study was assessed at the end of the interview using the Emotion Thermometers tool (see Appendix L; Mitchell et al., 2012). This tool provided an opportunity for participants to rate their level of distress, anxiety, depression, anger, and needing help on a scale of 10 (desperately need help) to 1 (I can manage by myself). This was then used to assess the participant's need for support. Adult participants who rated their distress as ≥8 out of 10 in their questionnaire were prompted to seek support and were given a brief telephone call to assess their mood within 48 hours of the interview and given further advice to seek support as per information provided at the time of the interview. Four participants (two fathers, one mother, and one grandmother) indicated a rating of 8/10. Two participants indicated they had already organised appointments with their GP/psychologist to seek additional support. All four were contacted after the interview, and all four indicated that they had organised additional mental health support.

It has been suggested that research participants often benefit from the experience, giving them the opportunity to explain their experiences and knowing they are benefiting others with similar experiences. In this study, 12 fathers added further comments that they appreciated the opportunity to discuss the experience as they felt they had not previously had an chance to discuss their feelings (Hannum et al., 2019).

Protocol for research with minors

This study involved interviewing children, and thus, we needed to ensure that we had age-appropriate ethical procedures. A child-friendly flip chart was developed with simple language and pictures/emojis to increase the children's understanding of consent. Various strategies were also used to develop rapport with children, including asking about school/hobbies, educational toys, and siblings showing photos. The researcher also provided participants with colouring pictures (either in person or emailed to parents) to give children an activity to engage them during the interview. During the research process, an ethics amendment was completed to request a short (10-minute) interview with parents/carers to gather information about the child's experiences; for example, if they had to live with grandparents or changed schools. This information enabled follow-up questions to be more targeted and increased the ability to develop rapport.

Expansion of research paradigm

To remain responsiveness to the data, several changes were made to the focus and structure of study processes throughout the course of the research. The three most significant changes were the inclusion of studies on COVID-19 and pregnancy and amendment to the siblings' study to focus on younger siblings. During the initial interviews, several participants mentioned the impact of COVID-19 and noted that experiences of the pandemic and associated restrictions were similar to their experiences of childhood cancer. After discussion with the research team, it was decided to add three additional questions to the interview guide covering aspects of COVID-19, and then prepare a manuscript to review this topic. Similarly, several of the first few interviews with mothers (and two with fathers) mentioned being pregnant when their child had cancer. A consumer representative who was the mother of a child with cancer and who was pregnant during the time of her child's diagnosis was consulted. Several questions were added, and a recruitment process was begun to specifically recruit mothers who had been pregnant when their child was diagnosed. A manuscript was then prepared to explore the experiences of mothers who were pregnant when their children were diagnosed. Another change to the research structure involved the decision to focus on younger siblings, During the initial interview process, it was noted that younger siblings had different responses to the two siblings over the age of 12. After a review of literature which demonstrated that most studies focused on older age or broad age groups, it was decided to focus the study on children under 12. Thus while two teenage siblings (14 & 15) were interviewed data from these interviews were not included in this thesis.

Another change involved a minor amendment to ethics, enabling a short phone call to siblings' parents to gather basic family information (diagnosis, length of treatment, and family dynamics). This was done to enable questions to be adjusted to suit family situations; for example, knowing if the child had to live with grandparents enabled specific follow-up questions to be included regarding care arrangements.

Several other minor adjustments were included, mainly involving adjusting to the circumstances surrounding COVID-19, this meant fewer interviews could be completed in person. Changes were thus made for example such as emailing colouring pictures to parents to give to siblings. One advantage of COVID-19 was that people became more accustomed to online technology, facilitating recruitment from rural areas and thus allowing a more diverse representation of experiences. An additional study was also added in response to participants' answers to the final question, "What advice you would give to parents whose child was just diagnosed with cancer?" Being a mother of a child who was diagnosed with cancer and having volunteered in the community for ten years, I felt that the information gained from answers would benefit other parents. After discussions with stakeholders, consumer representatives, and the supervisory team, an additional paper was prepared. The information provided is meant to be able to be used by the services that support families of children with cancer to help families as they negotiate the complexity of issues that arise when a child has cancer.

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CHAPTER 3 - Study 1: Parents' experiences of childhood cancer during the COVID-19 pandemic: An Australian perspective

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Chapter overview

This chapter presents the published findings from the first qualitative study, which explored the impact of COVID-19 on families of children with cancer. This research was conducted during the first year of the COVID-19 pandemic. Interviews were completed concurrently with recruitment; after the first five interviews, a common theme was seen with parents highlighting the similarities between the pandemic and their experiences of childhood cancer. I also found that the pandemic exacerbated some of the problems that parents encountered. Given the profound impact of the pandemic and the obvious lack of existing research on how it shaped parents' experiences, the research team developed two additional questions regarding COVID-19 which were incorporated into the interview guide to be used if the topic did not arise naturally. Interviews were completed with 34 parents (17 mothers and 17 fathers) to explore parents' perceptions of the impact on COVID-19 on their child's treatment for cancer. The data was analysed using reflexive thematic analysis, and five main themes were found. This article, "Parents' Experiences of Childhood Cancer During the COVID-19 Pandemic: An Australian Perspective", was published in December 2021 in the Journal of Pediatric Psychology, a peer reviewed journal that publishes articles related to theory, research, and professional practice in paediatric psychology (Davies et al., 2021). The article was also subsequently promoted on multiple news sites, newsletters, and as a feature story published in a Western Australian state newspaper in March 2022 (see Appendix A).

What this adds to the literature

The paper was one of the first studies to explore families' experiences of childhood cancer during the COVID-19 pandemic in Australia. This article provided valuable insights into the experiences of these families and the challenges they faced during the pandemic. My study revealed that many aspects of COVID-19, such as infection control and mask-wearing, benefited parents and their children. By showing the clear comparison between the significant changes that occurred due to COVID-19 and the normal experiences of children with cancer, this article was able to vividly demonstrate the overwhelming impact of childhood cancer on children and their families. It also provided insight into the wide-ranging ramifications of childhood cancer, highlighting that families of children with cancer experience changes to multiple domains of life, including school, work, and family interactions. It also emphasised the isolation and sense of loss that families experience when their children are diagnosed with cancer.

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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.

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 caseload 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 homeschooling, 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).

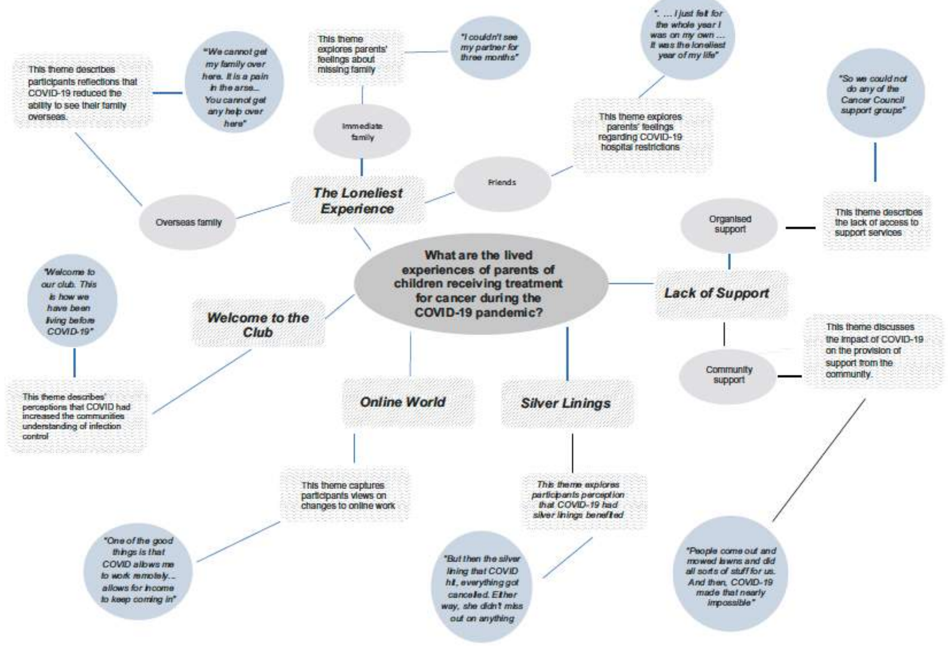

Figure 1. Thematic map.

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[a]	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

[a] 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 sniffle…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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Clinical recommendations

- The technological infrastructure developed during COVID-19 needs to be used to facilitate parents' ability to continue to work during treatment and assist families to access community services.
- Additional supports need to be provided to families of children diagnosed with cancer when restrictions prevent both parents from accessing the ward.
- Those who received diagnosis during COVID-19 lockdowns should be provided with long term follow-up care to assess and manage any negative psychological impacts.
- Community understanding developed during COVID-19 regarding infection control needs to be used to help educate the population regarding immune suppression in children receiving cancer treatment. This understanding is particularly relevant within educational settings.

CHAPTER 4 - Study 2: Fathers’ experiences of childhood cancer: A phenomenological qualitative study

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Chapter overview

This chapter consists of the second qualitative study of this thesis, which explored the experiences of fathers when their child is diagnosed with cancer. There has been very limited research on fathers’ experiences in this context, with most existing work focusing on mothers or parental dyads. The aim of this study was to examine the lived experiences of fathers during their child’s treatment for cancer. Participants were fathers of children aged 17 years and under who were currently receiving treatment for childhood cancer or had completed treatment in the previous 15 months. Twenty-one fathers were recruited from across Australia via social media posts and support organisations distributing flyers. These fathers were interviewed to gather information on their lived experiences, with the average interview lasting 62 minutes. Data was analysed using Braun and Clarke’s six-phase process. Five main themes were generated which demonstrated the impact of their child’s cancer diagnosis on fathers. This study was published in January 2023 in the *Journal of Family Nursing.* A peer reviewed journal which covers the topics of nursing research, practice, education, and policy issues in relation to family health (Davies et al, 2023).

What this adds to the literature

This research paper demonstrated the ways in which societal-cultural norms impact how fathers experience their child’s cancer diagnosis. Fathers still feel the need to be strong and receive messages from both family and HCP that their role is not to show emotions. This negatively impacts their experiences and denies them the opportunity to receive the support they need. This study emphasis the need for fathers to be provided with practical and psychological support that is tailored to their emotional needs. It adds to our understanding of their experiences, showing that they find witnessing their child’s treatment extremely traumatic and they need to be provided with more support and information to manage this stressor. In addition, this study provides an understanding the impact of death and loss on the ward, showing that fathers need to be provided with support to manage grief.

Research

Fathers' Experiences of Childhood Cancer: A Phenomenological Qualitative Study

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Abstract
Research has shown differences in how fathers and mothers respond to a child's cancer diagnosis. Previous studies have highlighted that sociocultural norm shape fathers' experiences of their child's cancer diagnosis. Our phenomenological qualitative study aimed to examine the lived experiences of fathers whose children have been diagnosed with cancer and explore the impact of sociocultural gender roles. Fathers whose children were currently receiving treatment or had completed treatment in the previous 15 months were recruited from across Australia. Twenty-one fathers were interviewed. Five themes were identified: (a) Your world falls apart: Diagnosis and treatment; (b) Care for the child: Just the way it is; (c) Keeping strong: Finding ways to cope; (d) Employment: Practical and emotional support at work; and (e) Guilt, relief, and grief: Facing death. This study demonstrates the profound impact of a child's diagnosis on fathers and demonstrates that societal–cultural norms influence fathers' experience of childhood cancer.

Keywords
qualitative, fathers, cancer, childhood

While childhood cancer impacts both parents, research has shown that there are differences in fathers' and mothers' experiences (Gibbins et al., 2012; Rensen et al., 2019). Studies have shown that mothers provide most of the direct care for the child during cancer treatment (Gibbins et al., 2012; Lewandowska, 2021; Rensen et al., 2019). Bennett Murphy et al. (2008) argue that this is because an ill child requires comfort during painful treatments and intense support to assist them in managing distress and, as normative societal gender roles typically place mothers in roles of nurturance and caregiving, children are more likely to seek maternal comfort. These authors suggest that childhood cancer can "amplify" gendered parenting roles and that the complexities of parental roles are often magnified under the stress of caring for a child with cancer. Fathers' needs and the impact of childhood cancer on them are often not acknowledged as the focus tends to be on the effect on the primary care giver.

However, childhood cancer has profound impacts on many aspects of fathers' lives. Previous reports have highlighted that fathers of children diagnosed with cancer typically continue to work to support their families financially (Brody & Simmons, 2007; Kelada et al., 2020; Robinson et al., 2019). This can create stress for fathers as they often feel they neglect caring for the child with cancer in favor of maintaining family income (Nicholas et al., 2009). Simultaneously, fathers may need to adjust to a new role as the primary caregiver to siblings, which changes how the family functions, and alters roles and responsibilities within the household (Hill et al., 2009; Silva-Rodrigues et al., 2016).

Studies on childhood illness have generally found that fathers feel excluded from many aspects of care. Hill et al. (2009) described how fathers whose children are ill may feel they have a secondary role to mothers and need to

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seek mothers' approval for decisions. This is described as "maternal gatekeeping," where fathers want to be involved, but mothers limit their involvement in day-to-day care within the hospital (Hill et al., 2009; Hovey, 2005). Reis et al. (2017) reported that fathers caring for a hospitalized child felt that the hospital was an unwelcome environment, with some reporting feeling "judged" by health care professionals (HCPs). It has been proposed that these feelings of being "sidelined" may increase the stress and trauma that fathers experience (Bailey-Pearce et al., 2018; Chesler & Parry, 2001; Yogman & Garfield, 2016). Fathers of children with cancer also report feeling the need to be strong and not express emotions (Hill et al., 2009). This, combined with societal structures and norms that discourage men from expressing feelings, means that support provided to fathers is often limited (Chesler & Parry, 2001; Hill et al., 2009).

It has been suggested that fathers are, in many ways, the "forgotten parent" with limited research exploring the impact of chronic illness on their social and emotional wellbeing (Archibald et al., 2021; Bailey-Pearce et al., 2018). There is a paucity of data on fathers' experiences when their child is diagnosed with cancer. Consequently, there is a need to develop a better understanding of the paternal experience of childhood cancer (Archibald et al., 2021; Brody & Simmons, 2007; Neil-Urban & Jones, 2002; Reis et al., 2017). In addition, most of the published qualitative literature specifically focusing on fathers' experiences of having a child with cancer was conducted over a decade ago.

In the previous decade, there has been a societal shift in fathers' roles in parenting in the general population, with a growing expectation that fathers play a more active role in caregiving (Banchefsky & Park, 2016; Borgkvist et al., 2020; Jones et al., 2021; Reis et al., 2017). However, the extent to which gendered parental roles have shifted may be culturally specific. Australia is a relatively "masculine society" with mothers providing more direct care for children (Australian Bureau of Statistics [ABS], 2018; Baxter et al., 2014; Borgkvist et al., 2018; Coles et al., 2017; Pfitzner et al., 2018; Stevens, 2015). Research is required to examine whether changing family roles have influenced the experience for fathers of children with cancer and to define the extent to which normative gender roles persist. This understanding can be used to inform effective and specific support services for fathers.

Research Aim

The aim of this study was to examine the lived experiences of fathers during their child's treatment for cancer.

Method

Study Design

This study employed a phenomenological approach that provides the opportunity to explore how people make meaning from their experiences (van Manen, 2017). Data were collected using qualitative interviews. This provided participants the opportunity to describe their experiences in their own words and enables the development of an in-depth understanding of lived experiences (Queiros et al., 2017). To assist participants in talking about their experiences, we used a semi-structured interview schedule, which allows a more informal way of communicating and has been found to enable the collection of rich data (Pietkiewicz & Smith, 2014).

The research was part of a larger study that uses the ecological systems theory to examine the experiences of individual family members (fathers, mothers, grandparents, and siblings). Ecological systems theory provides a vehicle for looking at the individual in a broader context and highlights that all individuals are nested within broader macro-cultural systems, which shape beliefs, gender roles, and influence how individuals perceive their experiences (Darling, 2007; Murrell, 1978).

Ethical Approval

Our study was approved by the Curtin University Human Research Ethics Committee (March 2021, HRE2021-0119).

Participants

Participants were fathers of children aged 17 years and under who were currently receiving treatment for childhood cancer or had completed treatment in the previous 15 months. Fathers of children who were receiving palliative care were not eligible to participate.

Recruitment

We recruited between March and June 2021 during the COVID-19 pandemic (Davies et al., 2021). Convenience and snowball sampling was used to seek out participants that met the inclusion criteria (Leavy, 2017). We placed notices on Facebook support group pages across Australia and flyers were distributed by Australian charities supporting children with cancer and their families. All recruitment strategies requested that participants contact the JD via email or a research-specific phone number.

Procedure

We provided all fathers who expressed interest with a participant information sheet. Those who agreed to participate were then contacted to organize interview times. JD conducted all interviews via teleconferencing ($n = 11$) or at a location suitable to participants ($n = 10$). Prior to the interview, all participants completed a consent form and a demographic questionnaire. Questions were generated through previous research and consultation with consumer representatives who were fathers of children who had been diagnosed with cancer. Examples of interview questions included "Could you describe the emotions and feelings that you experienced at diagnosis?" and "tell me about what it was like adjusting to life during your child's cancer treatment." The interview guide provided a framework, however, to allow for a more flexible interview process, questions were ordered differently between interviews. Interviews lasted an average of 62 minutes ($SD = 12$, range: 39-85 minutes). JD was mindful to ensure that participants were given the option to cease/pause the interview if they felt distressed and we provided all participants with details of relevant support services at the completion of the interview. We offered all participants a AUS$20 gift card to reimburse them for their time.

Analysis

Data collection and analysis occurred concurrently. Recruitment ceased once saturation had been reached, which was considered to have been achieved when there was sufficient richness and depth in the data, and no new themes were being identified (Guest et al., 2020; Mason, 2010). We thematically analyzed transcripts using Braun and Clarke's six-phase process (Braun & Clarke, 2006). Transcription occurred as soon as possible after each interview, either manually by JD or using Rev Transcript an online transcription service. After transcription, JD listened to the interviews (with necessary amendments made to ensure accuracy) to become familiar with the data. JD then reviewed transcripts to look for common patterns with notes recorded. Initial analysis was used to shape ongoing data collection and to refine interview questions as appropriate (Pope et al., 2000). This involved examining data for negative cases and seeking participants that provided further perspectives on the experience via alternative participant recruitment (Pope et al., 2000). JD read the transcripts, then developed the codes. MO and GH then reviewed the codes and made necessary changes to refine codes. During the coding process, all authors reviewed the themes. Finally, JD wrote the themes into a report to represent findings with quotes provided as exemplars for each theme.

Quality

The guidelines for Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed to ensure quality and rigor (Tong et al., 2007). JD kept a reflective journal throughout the process of research to record observations and responses to data (Berger, 2013; Johnson et al., 2020). In addition, a thorough audit trail was kept pertaining to all research processes and decisions. To enable member checking, we provided participants with an opportunity to examine preliminary themes (Tong et al., 2007). This involved randomly selecting six participants who were sent an overview of the main themes. Four participants responded, indicating that the themes were an accurate reflection of their experiences.

Findings

Our final sample consisted of 21 fathers, with an average age of 41 years (range: 33–51 years, $SD = 5$). We recruited participants from across Australia. The age of children at diagnosis ranged from 4 hours old to 15 years old. Seventeen (81%) of the children were still receiving treatment at the time of the interviews. Three fathers (14%) indicated their children were on treatment following a relapse. Further participant demographics are provided in Table 1.

We identified five main themes: (a) Your world falls apart: Diagnosis and treatment; (b) Care for the child: Just the way it is; (c) Keeping strong: Finding ways to cope; (d) Employment: Practical and emotional support at work; and (e) Guilt, relief, and grief: Facing death.

Your World Falls Apart: Diagnosis and Treatment

This theme explores fathers' responses and feelings regarding their child's diagnosis and treatment. Fathers described the initial diagnosis as a "life-changing moment." One father recounted how he felt that it felt like "your world falls apart." Most fathers explained how they had little understanding of childhood cancer as it was not something "discussed a lot by anyone." Most fathers also reported that their perception from society was that childhood cancer was something with poor outcomes "At that stage, we did not really know because all I could remember of leukemia . . . was that it was death sentence." These beliefs influenced their emotions when they first heard their child's diagnosis "That was the first thing that you think of when you hear of cancer oncology in a child is like . . . death . . . how is he going to survive this, will he die?" One father observed that in movies kids with cancer "always die." Many participants also reflected it was hard to process the experiences "you are discovering new emotions . . . these are emotions you are not meant to feel." Several fathers described their first experiences on the ward as one of the most difficult:

> You get down there and hear these poor little kids going, "No, please. No," and "I cannot do it." You think, "Oh my God, this is . . . it was almost like entering the pits of hell." Those doors slide open, you're in there and that was it, that turning point in your life.

Fathers reported experiencing distress associated with time spent caring for children in the hospital and watching them experience painful procedures. Many explained they felt helpless because, as one father stated, "I couldn't protect her from the pain and there was so so much pain . . . she was so little." One area that fathers reported as being particularly challenging was having to restrain their child for procedures with one father saying,

> Just the anticipation . . . the anxiety of going into that room and lying there . . . "Dad, this is going to be horrible," then holding his hand. He'd cry . . . that isn't something any parent should have to do.

Table 1. Sample Socio-Demographics (N = 21 Participants).

	n	%[a]
Marital status		
Married	18	86
De-facto	2	10
Stepfather	1	5
Educational		
Year 12	3	14
TAFE/local college	6	29
Bachelor	8	38
Post-graduate	4	19
Changed work status		
Yes	7	33
No	14	67
Child's primary diagnosis		
Brain cancer	2	10
Sarcoma	4	19
Hematological	10	48
Neuroblastoma	3	14
Lymphoma	1	55
Other	1	5
Child diagnosed with cancer gender		
Male	13	62
Female	8	38
Siblings of child with cancer		
0	3	14
1	10	48
2	6	29
3	1	5
≥ 4	1	5

[a]*Percentages may not add to 100 due to rounding.*

Steroids were highlighted by many fathers as one of the most difficult parts of treatment. One father described,

> [child diagnosed with cancer] is just absent-minded and . . . hyperactive and cannot control his mouth at the time and just the usual . . . but you still do have to make allowances. Because it is really hard for him to control those impulses when he is on the steroids.

Fathers discussed the difficulty of managing the increased appetite "Well, it was shocking. In the 28 days, I was preparing four meals a day plus snacks. He was just eating and eating." Many fathers indicated that they were not always given enough information to prepare for these changes "That was the worst part. I say the worst part. I wasn't aware. If I had one criticism through the whole process, I wasn't aware the drug was going to have such an effect on her tiny body." Several fathers commented that they did not have parental skills to manage this change and knew "it wasn't [child diagnosed with cancer], just the drugs," but questioned "how they should parent a child who behaved like that?" Several participants felt that mothers "were better able to cope" with these changes in personality and behavior:

> I was a crap dad . . . [mother of child with cancer] just did it . . . I felt angry with [child diagnosed with cancer] and then felt guilty that I didn't know how to parent him . . . no one wants to feel like a bad parent . . . but I did then I would just leave which I know my wife didn't like . . . it is just all so hard.

It would appear that these emotions and fears regarding their ability to cope with changes in behavior exacerbated the feeling that their world was falling apart and made them question their parenting skills.

Care for Their Child: Just the Way It Is

This theme captures participants' responses to questions regarding caring arrangements for the child with cancer and their feelings regarding their ability to be involved in care of their children. The majority of fathers reported that the mother provided most of the care during hospitalizations and outpatient appointments. Fathers reflected that in most cases, it was an "automatic process," and when asked how decisions were made about who stayed with the child, many described it as a "natural process" because of the child's connection to their mother. One father described how "[child diagnosed with cancer] has more of an affinity with mum." Overall, fathers accepted the roles of mothers and the bond that children, particularly very young children, had with their mothers.

In many cases, fathers reported that they perceived mothers felt a need to be present with the child and assume a greater role in their care. Fathers felt that they were supporting their partners by allowing them to adopt a greater share of care for the child with cancer. "I knew that [my wife] needed that as well. It was more about [child diagnosed with cancer] and [my wife] than it was about me, and I knew that was best for both of them." Participants in the study did not express resentment toward their partners for performing the majority of the caring role and reported that they did not feel that they were prevented from participating in caring for their children. In fact, many spoke of the admiration and appreciation they had for the role their partners played "[my wife] had to basically put her whole life on hold and do everything for [child diagnosed with cancer]."

Some fathers described a shared care arrangement where they would alternate nights in the hospital, with one father highlighting how he "wanted to be with [my child with cancer] when she needed me." Several of these fathers commented that this shared arrangement reflected the shared roles they normally performed in the home "we share everything normally, so we just kept doing that." This also impacted care of siblings and the home "we do most things as a team anyway, and so when one of us was in the hospital, it just became the new normal that the other person would take care of as much as they could in the house."

When discussing care and treatment of their children, fathers indicated that health professionals did not treat them differently and, as one father commented, "the doctors were great at making sure we were always both there for when discussing treatment options" and another commented that the nurses always "encouraged him to help out with stuff." No fathers expressed any concerns regarding their ability to be involved in treatment or provide care for their child.

Staying Strong: Finding Ways to Cope

This theme explores how fathers approached the experience of their child being diagnosed with cancer. The majority of fathers described internal and external pressures to "be strong" and not show emotion. For example, one father of a child stated, "I needed to be strong. For [my wife] and [my children] . . . I couldn't break down and . . . cause any more anguish . . . I needed to take that kind of leadership role." Fathers also outlined how they felt the need to reduce the burden on their partners:

> So, I felt my duty to try and keep up to date with everything and tell everyone . . . I was trying to relieve some pressure from [my wife] . . . I took it upon myself to do that, I didn't really ask for support.

In multiple instances, fathers recounted examples where friends, family, and even HCPs had told them that they needed to be strong and not express stress or sadness. One father remembered a social worker telling him,

> Your whole family is about to fall apart around you because of this. Everything can go to shit, but what you have to do is you have to hold it together. Don't show your [child diagnosed with cancer], your wife, and the disease any form of weakness . . . You need to bottle, just hold it in. Go and cry in the shower if you have to. Do what you got to do, but just don't let it out in front of your family.

Another father recalled,

> I feel like there's a need to be strong. We did have a weird change in role, we're always equals in a lot of ways, but then a lot of messaging I got from friends and family is you've got to be strong for [my wife]. As if I'm not allowed to have feelings too, be vulnerable.

In some instances, this caused tensions between fathers and their partners:

> Always trying to be brave. That's one of the things that I think sometimes does cause a bit of a clash between me and [my wife], is that I try and be brave and not cry and not show emotion in front of her . . . It doesn't always work and sometimes does cause a bit of conflict as my wife thinks I don't feel anything.

Fathers described avoiding rumination with a focus on not showing emotions or being "weak." Fathers explained how they focused on the "here and now," with one father stating that he "just [had] to get on with it . . . just take it as it comes." This tendency to cope by remaining focused on the immediate situation was echoed by another father, who commented "Don't dwell . . . I don't want to be focusing too much on the bad stuff . . . putting my energy into that because it brings me down."

Many fathers, particularly of children with lower-risk cancers, such as acute lymphoblastic leukemia, also coped with the stress by comparing their child's cancer with other cancers and framing it as the more favorable cancer, for example, "she has the best of it, or should I say if you can pick a leukemia to have, you have always got favourable." Often, these approaches were adopted because they wanted to protect their children with one father commenting: "You've just got to be positive for [child diagnosed with cancer] . . . and see the bright side . . . it's my role to keep it together."

While fathers reported that they tried to stay strong and cope, several also acknowledged the impact of being strong for their families. One father who had been told to be strong by a HCP indicated that this comment had a profound impact, and he felt that subsequent severe mental health issues were a result of this focus on "being strong." When asked what advice they could give to a father with a recently diagnosed child, the majority of fathers (75%, $n = 16$) highlighted the need to ask for support and talk to others. One father remarked "As a dad, seek [support] out and accept it. Accept the help. Don't just say it should be all right." Another commented "We have . . . this macho thing, I don't need help . . . no we all need help in a way." For fathers whose child was at the end of treatment or had recently completed treatment, many expressed that they were having difficulties managing their psychological wellbeing. Several commented that seeking support would have been helpful; for example, a father whose child had recently completed treatment commented "Maybe I wouldn't feel so bad now if I had asked for help."

Employment: Receiving Practical and Emotional Support at Work

This theme reviews fathers' reflections on their employment. The majority indicated that their workplaces were extremely supportive, practically, and emotionally. This support seemed to occur in various work situations, including those employed by large corporate companies, public sector, and small companies. When asked, one father recalled,

> The boss sat with me, and he said, "Mate . . . You don't have to worry about anything." He said, "Whatever happens. You don't have to worry. Okay? Just get through this." That was fantastic . . . I didn't have to fill in a sick-leave form. I had it all up my sleeve, hundreds, and hundreds of hours.

This was aided in many ways by the COVID-19 restrictions in place at the time, which made working from home/hospital easier, with one father making the comment,

> I worked from [hospital] . . . I just obviously put [child diagnosed with cancer] first and then worry about work later, but now since his diagnosis, they've written up a flexible working remote arrangement [during COVID] so I can work remotely from hospital.

However, for self-employed fathers, this posed additional challenges, for example:

> That is the challenge for those who were self-employed actually, talking to people about it and that sort of stuff I found really hard. I did not really have a choice. I had to do it because I am self-employed. When people ring me to come to do their work, I am unavailable. Then, they need to know why . . .

However, while noting the difficulties being self-employed created, it did not seem to cause significant stress, with one father who was self-employed observing "That really it wasn't a big deal . . . and we found a way to make it work . . . people were generally great." Several fathers who continued to work on-site indicated that work provided benefits including the ability to not think about their child's diagnosis:

> With having the ability and going to work, I probably have coped better than [my wife], in that respect that I can get away from it, switch off, so to speak. Come in and focus everything on work and then come back . . . work I have found it is a way to cope.

Most fathers acknowledged the financial impact of cancer, mainly from their partners giving up work, but did not highlight that their own work income had been significantly affected. For example, "there is some financial stuff, which you take a little while to clear up, but it is not insurmountable. It is not unfixable."

Guilt, Relief, and Grief: Facing Death

Fathers who had spent time on the ward reflected on the impact of knowing families whose children died from cancer. Fathers experienced a conflicting spectrum of emotions, feeling both relieved that their children were comparatively well, grief for the loss of the other children they knew from the ward who had passed and feelings of guilt that their children were alive while the deceased child's family grieved:

> Oh yes, Jesus . . . Parents are not meant to bury their kids, the kids are meant to bury their parents. Especially like that, you have been given such hope and then it all goes backwards again like you know what I mean? That is crazy. Poor, old [father of deceased child], like Jesus . . . When he asked about [my child diagnosed with cancer], it is hard to say when she is going great . . . It is kind of like, fuck.

Another commented in tears "I have seen three kids die . . . That was shitloads." These examples reveal the overwhelming distress caused by witnessing the death of children. In addition, fathers also mourned that their children, who sometimes grew close to children who eventually died, experienced grief and loss at such a young age:

> It is horrible. No kid should have to go through that . . . you develop a bond. And [my child with cancer] went on camp with a few of these kids . . . and kids he knew have passed . . . that's not right.

Most fathers reflected that the awareness that children have died changed them as people making them more focused on the "important things." They also reflected that there was "no way they could talk about this with other people" leaving them feeling "isolated and not part of the normal world . . . people just don't get it, and no one wants you to talk about . . . like somehow it is catching."

Discussion

Our qualitative study contributes to an understanding of the lived experience of fathers whose children have been diagnosed with cancer. This study demonstrates the profound impact of a child's diagnosis and treatment on fathers. The fathers in this study described the immense distress associated with their child's cancer diagnosis and treatment. We found that societal values, expectations, and gender roles appear to influence how fathers respond to their child's cancer.

In our study, fathers reported that each parent performed different roles and that, despite shifting societal norms surrounding parenting, there remained an implicit assumption that mothers would provide the majority of day-to-day care for their child with cancer (Jones et al., 2021; Reis et al., 2017). Goldscheider et al. (2015) contend that while women have an increased role in the workforce, they are still expected to carry a larger burden of care for children and that this impedes a true "gender revolution." It appears in our study that traditional roles are still accepted, and this was largely seen as the "natural" response. There seemed little resistance to traditional roles of the mother providing the primary caregiving role and, in fact fathers expressed appreciation and admiration for the roles that mothers took in caring for the child with cancer (Hill et al., 2009). This implies that while discourse around fatherhood and parenting may suggest that fathers have increased their participation in parenting, under the stress of cancer diagnosis there appears to be a reliance on traditional-gendered caregiving roles (Bennett Murphy et al., 2008).

Cultural-gendered roles and expectations also appear to have impacted fathers' emotional responses to their child's cancer diagnosis. Banchefsky and Park (2016) observed that men are socialized to approach issues differently, focusing less on emotions and more on "coping" and accepting situations. This is evident in our study, as fathers used multiple strategies to adapt to the situation and minimize their emotional response. Decisions and responses to the diagnosis and treatment appear to have been guided by social–cultural values of masculinity. After the initial shock, fathers in our study appear to have adopted a problem-focused coping approach, focusing on the immediate situation to cope with their child's diagnosis. This is consistent with previous research regarding fathers' responses to childhood cancer (Brody & Simmons, 2007; Chesler & Parry, 2001; Hill et al., 2009; Neil-Urban & Jones, 2002). Fathers expressed a need to be "strong" for their family (Chesler & Parry, 2001; Hill et al., 2009; Nicholas et al., 2009; Robinson et al., 2019). Interestingly this need to be strong was explicitly reinforced by others, revealing that sociocultural norms requiring men to be "strong" are still prevalent despite changing roles of fathers.

Interestingly, while our study also supports previous research that fathers often mask their feelings to support their partners (Higham & Davies, 2012; Hill et al., 2009; Neil-Urban & Jones, 2002), this study found that fathers acknowledged that this adherence to gendered roles was not always in their best interest. Fathers whose children had recently completed treatment or were in later stages of treatment reflected that "bottling up" their emotions and feelings made it harder to deal with the emotional and psychological toll of their child's cancer in the long run. There appears to have been a tension between following the traditional gendered roles and being aware of their own feelings and needs.

While the majority of fathers in our study indicated that mothers took on most of the care for their child with cancer, some fathers outlined how they shared the care of their child equally with their partners, including taking turns spending the night in hospital. Fathers in the current study who wanted to be involved in caring for their child appeared to have faced fewer obstacles than has been reported in previous studies (Bailey-Pearce et al., 2018; McGrath & Huff, 2003; Reis et al., 2017), and none reported feeling uncomfortable or "sidelined." In addition, there appears to have been a shift in the approach from HCPs unlike previous research by Reis et al. (2017) and Bailey-Pearce et al. (2018) fathers did not perceive that the HCP limited their involvement in the care of their children, and all fathers felt that HCP included them in all decision-making. In this aspect, while roles are still often performed along traditional gender roles, the HCPs appear to have modified attitudes and behaviors to include fathers in decision-making processes regarding their children's treatment plans. To date, there has been limited research specifically investigating paternal experiences of childhood cancer in Australia and the impact of gender norms. This study extends our understanding, highlighting the tension between broader cultural expectations that fathers remain stoic, a tendency for families to default toward traditional parenting roles, with a health care system more inclusive of fathers' involvement. This demonstrates a changing, yet not transformed, landscape for fathers and highlights the potential for HCPs to facilitate greater involvement and challenge gendered expectations.

Another aspect that may indicate some changes in fathers' role in care relates to fathers' descriptions related to witnessing aspects of their child's treatment. Many fathers highlighted the trauma of restraining their children during painful procedures and feeling ill-equipped to manage steroid-associated behavioral changes. In this study, while mothers provided most of the care, fathers described being engaged in care for their children during treatment. This finding differs from previous studies, which did not highlight fathers' perceptions of treatment and involvement in care (Brody & Simmons, 2007; Chesler & Parry, 2001; Hill et al., 2009). This indicates that while mothers still provide the majority of care, fathers have increased their caregiving roles within the hospital and are thus more exposed to the traumatic aspects of treatment. However, while our study did show that many fathers were involved in various aspects of treatment, many fathers felt that they were less prepared than mothers to handle some of the complexities and trauma of treatment.

Previous studies have described the tension fathers experience between the need to provide financially for their families while taking care of their children (Brody & Simmons, 2007; Higham & Davies, 2012; McGrath & Huff, 2003; Neil-Urban & Jones, 2002; Nicholas et al., 2009). In our study, fathers did not appear to demonstrate this tension, which may be partly due to the COVID-19 pandemic increasing the ability to work remotely (Davies et al., 2021). While family income was reduced due to changes in mothers' work, there appeared to be minimal stress regarding fathers' ability to provide an income, and fathers did not highlight the reduction in their income as a significant area of concern. This differs to previous studies (Brody & Simmons, 2007; Nicholas et al., 2009) where fathers expressed significant concern about their ability to provide income for their family. For self-employed fathers, however, there were tensions between balancing work and caring for their child with cancer. Nonetheless, most of these fathers reflected they were ultimately able to balance these competing demands. In addition, many fathers reflected that rather than work being a stressor, going to work provided an opportunity to "escape" the stress of their child's cancer (Hill et al., 2009).

It would appear that representations of childhood cancer in popular culture influence how fathers process the initial diagnosis (Foley et al., 2019; Green, 2006). Many fathers highlighted their lack of understanding of childhood cancer, and several fathers observed that the representations of childhood cancer in popular culture, which generally included children dying, made fathers fear the worst outcome for their children, particularly in the initial period following diagnosis.

Another way in which wider cultural values and expectations impacted the experience was around the issue of death and grief. Fathers in this study described forming a bond with other parents and children on the ward and described the trauma associated when children, whom they had formed a bond with, passed away. As observed by Longbottom and Slaughter (2018), changes in society and lowering of childhood mortality rates means people in developed countries generally have minimal exposure to the death of children. In our study, fathers described how in modern-day society they and their children had little experience or knowledge of how to process the death of children and that it was not something they could talk about with others. Participants reported intense, conflicting emotions regarding this experience, and saliently there was a lack of support from the general community and the health care system provided to assist fathers in navigating these emotions.

Limitations

One methodological issue with this study is that the sample was drawn from across Australia via organizations and social media sites that support families of children with cancer. Therefore, our sample may have been influenced by self-selection bias, and fathers who were not engaged within the cancer community may not have been included in our study. This study did not capture the experiences of same sex families, and there were only two fathers in a shared custody arrangement. It is also worth noting that our study was conducted in Australia, which is a high-income country with a universal health care system, so the majority of medical costs, such as hospital admissions and surgeries, are funded by the government. This may reduce the out-of-pocket expenses and incumbent financial stress compared with countries that do not provide universal health care. In addition, although there has been a shift in Australian expectations of masculinity and fatherhood, with increasing participation of mothers in the workforce, research highlights that in Australia, there is a persistent division of parental duties, with both societal and familial expectations that mothers provide a greater burden of care (Borgkvist et al., 2018; Coles et al., 2017). Notably, this experience is informed by cultural settings, for example, in Scandinavian countries, with more established gender equity polices and cultural practices, gender differences may not be as pronounced, and further research is required to elucidate these if there are cultural differences between countries (Borgkvist et al., 2018).

The sample also lacked extensive diversity in ethnic background with only one participant identifying from a culturally and linguistically diverse (CALD) background. Measures were taken to try to address this issue, such as seeking participants from CALD backgrounds via snowballing, but several families from CALD backgrounds declined to participate. This may be reflective of concerns regarding language issues; interviews were conducted in English, which could have excluded some CALD parents. We also did not have any fathers in our sample who identified as Aboriginal or Torres Strait Islander.

Clinical Implications and Future Research

Our study suggests that services need to be provided to acknowledge fathers' unique approaches and provide support designed to accommodate their individual needs. It would also be beneficial if HCP were provided with information of how fathers of children with cancer approach the experience, allowing for information and communication to be refined and improved. This includes understanding the duality between fathers' perception that they need to be "strong" and their own personal needs for support. Given that some fathers reported that this focus on being strong and not expressing emotions had negative long-term impacts, it would be beneficial to explore methods to assist fathers in accepting that expressing emotion and need for support may support their long-term psychological wellbeing. This may include delivering support in non-traditional formats, such as peer-led activities that enable fathers to get support from each other rather than from formalized therapy.

Fathers in this study whose child's treatment protocol included steroids outlined that they found this aspect of treatment especially difficult to manage. While the behavioral changes as a result of steroids therapy cannot be avoided, it is recommended that fathers and families are provided with additional clear education prior to the commence of steroids describing potential side effects, including anger, sleep disturbances, and appetite changes (McNeer & Nachman, 2010). Fathers need to be provided with specific advice for managing changes in mood and behavior. It may be of benefit to have psychological staff assist in this process to provide information on parenting techniques and coping and stress management strategies to manage their children's emotional reactions. Needle-related procedural pain, and the associated need to hold their children down was also highlighted by fathers as an aspect they found hard to manage. Recent research exploring ways to manage pain in children has demonstrated that various psychological interventions, such as the use of virtual reality, can significantly reduce the pain and anxiety for children (Birnie et al., 2018; Gerçeker, et al., 2021; Lluesma-Vidal et al., 2022). The use of these strategies is highly recommended as it has the potential to reduce the child's pain and thus reduce stress experienced by fathers. One important measure may be to encourage opportunities for fathers to connect with other fathers who are going through similar situations. Psychological support should be made available to assist fathers to manage the stress and grief regarding the death of children on the ward. Future studies are needed to assess the long-term psychological impact on fathers who witnessed loss of children on the ward to determine their need for additional grief support.

Conclusion

The findings of our research add to our understanding of childhood cancer specifically providing insight into how fathers respond to their child's diagnosis and treatment. This study demonstrates that fathers are explicitly and implicitly influenced by societal expectations and gender roles. Cultural norms appear to be changing but they are still present and powerful, and fathers often adopt approaches that focus on traditional masculine traits, such as "strength," which means their own needs are often neglected. Our study expands upon our existing knowledge to show that while fathers attempt to be strong witnessing their children experiencing treatment is traumatic and they need to be provided with more support in order to reduce the long-term negative consequences. It is envisaged that increased understanding developed via this study will enable care delivered by nurses, doctors, and medical staff to be tailored to fathers' specific needs thus reducing stress and anxiety for fathers.

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Moira O'Connor, BA (Hons), MSc, PhD, is an associate professor and senior research fellow at the School of Population Health, Faculty of Health Sciences at Curtin University in Western Australia. She studies the psychological and psychosocial aspects of cancer and palliative care and works with patients, families and carers, and health professionals. She has a keen interest in children, adolescents and young adults (AYA) affected by cancer (parental cancer, siblings of children diagnosed with pediatric cancer, and children and AYA diagnosed with cancer). Her recent publications include "'It's Always Been a Second-Class Cancer': An Exploration of the Experiences and Journeys of Bereaved Family Carers of People With Sarcoma" in *Cancers* (2021, with G. Smith et al.), "A Systematic Review of Interventions to Reduce Psychological Distress in Pediatric Patients Receiving Radiation Therapy" in *Patient Education and Counseling* (2019, with G. Halkett), and "'Torn in two': Experiences of Mothers Who Are Pregnant When Their Child Is Diagnosed With Cancer" in *Qualitative Health Research* (2022, with J. Davies et al.).

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Clinical recommendations

This study highlighted that more support needs to be provided to fathers that is designed to meet their individual needs. Some suggestions are as follows:

- It would be beneficial for HCP to be given information via hospital-based staff development on how fathers experience childhood cancer. This would include explanations of the fact that fathers feel the need to be "strong" and often are reluctant to express their need for support.
- Fathers whose children are receiving steroids as part of their protocol need to be provided with more specific information on behavioural and appetite changes. Support needs to be given to fathers to manage these side effects, including HCP offering parenting technique suggestions and coping strategies to help fathers parent children who are experiencing childhood cancer treatment.
- Measures need to be introduced to help children with needle-related procedural pain to reduce the stress on both the children and fathers including use of virtual reality and games to distract children.
- Psychological services should be offered to fathers to help them deal with the complexity of emotions, including the grief experienced when witnessing children with cancer who die as a result of their cancer diagnosis.
- Fathers need to be encouraged to connect with other fathers of children with cancer to share experiences and receive peer support.

CHAPTER 5 - Study 3: 'Torn in two': Experiences of mothers who are pregnant when their child is diagnosed with cancer.

Chapter overview

This chapter consists of the third qualitative study of this thesis. The original thesis proposal sought to explore mothers' experiences of childhood cancer, and the first six interviews of mothers included four mothers who had been pregnant and/or had a newborn when their children were receiving cancer treatment. This highlighted the complex issues that these mothers experienced in fulfilling their roles of mothers to an unborn baby/child and a child in treatment for cancer. A literature search revealed that no previous studies had been completed on this specific issue. Recruitment was therefore adapted to specifically recruit mothers who had been pregnant or had a newborn, with five additional questions added to the interview guide to explore this topic.

The aim of this study was to explore the experiences of mothers who were pregnant and/or had a baby while their older child was receiving treatment for cancer. Thirteen mothers were recruited from across Australia via social media notices and distribution of flyers. Data was analysed using reflexive thematic analysis and Braun and Clarke's six phase process. Six themes were found. This study was published in December 2022 in *Qualitative Health Research*, a peer reviewed journal which aims to further the development and understanding of qualitative research in health care settings (Davies et al, 2022). This study highlighted that mothers do not receive adequate psychological and healthcare support.

What this adds to the literature

This article provides an important understanding of the experiences of mothers and the complexity of managing the competing demands of a child in treatment and the needs of a pregnancy/newborn. It provides novel information which highlights the need to provide comprehensive support to mothers who are pregnant while their child is in treatment for cancer. Current hospital structures make it difficult for mothers to provide care to both a child with cancer and a baby. In Australia mothers are not provided with practical and psychological support to ensure the health of both the mother and the baby. This research adds vital information to the literature which enables services to be put in place to support mothers who are pregnant when their children have cancer.

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‘Torn in two’: Experiences of Mothers Who Are Pregnant when Their Child Is Diagnosed With Cancer

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Abstract

Mothers of children diagnosed with cancer have been shown to experience high rates of psychological distress and poor physical health. Pregnancy further increases the healthcare needs of mothers due to the marked physiological changes and psychological adaptations. Our study aimed to explore the experiences of mothers who were pregnant and/or had a baby while their older child was receiving treatment for cancer. Our study employed a qualitative description methodology using semi-structured interviews. Participants were recruited from across Australia via notices on social media sites and the distribution of flyers. The sample comprised 13 mothers who were pregnant and/or had a baby and had a child diagnosed with cancer who was under 17 years old. Thematic analysis was used to analyse the data from which six themes were identified: (1) an impossible balancing act, (2) mother’s health and well-being, (3) creating certainty: birthing plans, (4) a bit of sunshine and a time to rest, (5) challenges of caring for the baby and (6) an unenviable position: doing my best versus feeling guilty. Our study demonstrates the additional challenges faced by mothers who are pregnant while their child is receiving cancer treatment. There is a need for a comprehensive and coordinated program that provides pregnant mothers with practical and psychological support. The implementation of such a program has the potential to improve health outcomes for all family members, particularly the mother and their newborn.

Keywords
cancer, qualitative, childhood, paediatric, oncology, pregnancy, baby, midwifery

In Australia, it is estimated that over 800 children aged under 15 years are diagnosed with cancer each year (Youlden & Aitken, 2019). In recent decades, there has been an increase in incidence rates from 128 children per million in 1983 to 171.5 per million in 2015, meaning that an increasing number of families are having to contend with the challenges of a child’s cancer diagnosis (Cancer Council Queensland, 2019). Of these families, almost half (47%) of all childhood cancers are diagnosed in children aged 0–4 years (Youlden & Aitken, 2019). When this is coupled with the fact that women on average have 1.74 children with a gap of 18–24 months between each child, there will inevitably be a significant number of pregnant mothers whose children are undergoing cancer treatment (Australian Institute of Family Studies, 2020). These mothers face a multiplicity of challenges in navigating the conflicting demands of caring for their child with cancer, managing their perinatal care and caring for their baby.

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Background

The diagnosis of childhood cancer creates a crisis in the family and includes many stresses (Compas et al., 2015). All energy is focused on the child and their recovery, and parents' needs are often neglected (Cox, 2016; McEvoy & Creaner, 2022). Treatment protocols for childhood cancer are complex, and parents have to witness their child receiving a range of treatments, which can include chemotherapy, radiotherapy, surgery, stem cell transplants and adjunct medications, which often require long periods of hospitalization (Castellano-Tejedor et al., 2017). Alderfer et al. (2005) observe that there is considerable variation in how parents experience childhood cancer depending on the length of treatment, diagnosis, physical impacts and treatment progress. However, studies have demonstrated that a child's cancer diagnosis has profound psychological and physical effects on parents (Bemis et al., 2015; Castellano-Tejedor et al., 2017; McInally & Willis, 2017; Schepers et al., 2017). Numerous studies have reported that parents of children with cancer exhibit high levels of depression, anxiety and reduced quality of life (QoL) during the child's treatment (Klassen et al., 2008; Sulkers et al., 2014). The impact can be wide-reaching and multifaceted, as the diagnosis affects many aspects of family life, including friendships, work, finances and personal identity (Al Omari et al., 2021; Kahriman et al., 2020; Wakefield et al., 2014).

Research has also shown that mothers often experience significant disruption in their lives after a child's cancer diagnosis (McEvoy & Creaner, 2022). Bury (1982) articulates this as the theory of biographical disruption, arguing that a diagnosis of serious illness (or that of a loved one) disturbs the narrative individuals hold regarding their future life and their self-identity. This model is useful for articulating the stressors that mothers experience when their child is diagnosed with cancer (Davies & O'Connor, 2022). Research has shown that while the stress of a cancer diagnosis is shared by all caregivers, mothers carry a disproportionally larger burden of care (Al-Gamal et al., 2019; Silva-Rodrigues et al., 2016; Wilford et al., (2019). A systematic review concluded that there was a trend towards traditional gender roles, with mothers taking on 'caring roles' which correlates with higher rates of psychological distress (Clarke et al., 2009). Consistent with this, a more recent report revealed that 85.5% of families identified the mother as the primary caregiver and that this caring role was associated with detrimental changes in psychological wellbeing (Katz et al., 2018). This has been speculated to be a consequence of mothers staying with the child in the hospital and thus being exposed to more trauma in witnessing their child undergoing painful procedures (Vrijmoet-Wiersma et al., 2008). In addition to increased levels of stress and anxiety, mothers of children with cancer have been shown to have a poor QoL (Clarke et al., 2009). Studies have also shown that taking care of a child with a serious illness affects a mother's ability to care for her physical health, which includes her sleep and nutrition (Eyigor et al., 2011; McEvoy & Creaner, 2022).

Pregnancy is a period of increased healthcare needs, including nutritional support, prenatal care and monitoring, in addition to management of any comorbidities (Englund-Ögge et al., 2015). Pregnancy is also associated with marked physiological adaptations that can lead to a plethora of symptoms, such as musculoskeletal pain, which may impact a mother's activities of daily living and sleep (Ceprnja et al., 2021). Studies have also shown that maternal exposure to stress increases glucocorticoid levels during pregnancy, which has a significant impact on the health outcomes of both the mother and the child (Abdi et al., 2016; Hamada & Matthews, 2019; Kashanian et al., 2019; Poston et al., 2011). Moreover, stress during pregnancy is associated with shorter mean gestational duration and an increased risk of preterm birth (Mirabzadeh et al., 2013).

The need for additional healthcare for mothers continues beyond the birth of the baby and there is a growing awareness of the importance of the early neonatal period (the 12 weeks after birth) as being crucial to maternal and child wellbeing (Cornish & Dobie, 2018). This period has been dubbed the 'fourth trimester' and represents a period of enhanced need for support for both mother and baby (Cornish & Dobie, 2018). The neonatal period is normally a time of adjustment in balancing roles of caring for the baby and sibling/s, managing sleep deprivation and adapting to new routines and changes in relationships (Cornish & Dobie, 2018; Savage, 2020; Spelke & Werner, 2018; Tully et al., 2017). Lack of support may have detrimental impacts on maternal wellbeing, and post-partum mothers with minimal support are up to five times more likely to develop post-partum depression (Kim et al., 2014).

Families with both a child with cancer and a baby face additional psychosocial stressors during an already vulnerable period and are tasked with adapting to a new way of life with both a sick child and a baby. There appears to be no specific qualitative research that explores the experiences of mothers who are pregnant while their child is receiving treatment for cancer. To identify potential avenues to reduce the burden and stress in this vulnerable population, we sought to improve our understanding of the experiences of pregnant mothers of children with cancer.

Aim

Our study aimed to explore the experiences of mothers who were pregnant and/or had a baby while an older child was receiving treatment for cancer.

Method

Our study used a qualitative description approach, which seeks to describe and understand a phenomenon, and is considered particularly valuable for research exploring healthcare settings (Bradshaw et al., 2017; Chafe, 2017; Sandelowski, 2000, 2010). This was deemed a suitable approach as we were not seeking to develop 'conceptual knowledge' but to explore and determine the need for improvements in the quality of care and support provided to mothers in paediatric oncology settings (Chafe, 2017; Neergaard et al., 2009). We used semi-structured interviews to gather data. This method is flexible and provides an opportunity to gather information related to the research question while allowing participants to provide their narratives and descriptions of their experiences. We used an interview guide (provided at end of the manuscript), and interview questions were developed in conjunction with a consumer representative. The consumer representative was a mother who had been pregnant while their older child was receiving treatment for cancer. Curtin University Human Research Ethics Committee approved our study in March 2021.

Participants and Procedure

Eligible participants were mothers who were pregnant or had a baby while their children were receiving treatment for cancer. Children with cancer needed to be aged under 17 years and be currently in treatment or had completed treatment in the previous 15 months. Parents who had experienced bereavement through the loss of a child due to cancer were not eligible for participation. We recruited participants via convenience sampling with notices placed between March and July 2020 on Facebook sites and distribution of flyers via multiple Australian organizations/groups that support families of children diagnosed with cancer. We also used snowball sampling to recruit mothers who were pregnant while their child was in treatment for cancer.

Potential participants were requested to contact JD via email, and we then sent them study information and consent forms and responded to participants' questions. JD conducted all interviews either via teleconference or in person at a venue of participants' choosing. JD verbally explained the participants' rights before the commencement of all interviews, including the right to withdraw. With participant consent, all interviews were digitally audio-recorded. At the completion of the interview, we gave all participants information on relevant support services, and we offered a AUD$20 gift card as a thank you and acknowledgement of their time.

Data Analysis

Data collection and analysis occurred concurrently. We continued recruitment until it was considered that the data being analysed contained an in-depth exploration of participants' experiences. As observed by Moules et al. (2012), data collection can never be 'complete' and qualitative research seeks to obtain rich data that provides a textured understanding of people's experiences (Hennink et al., 2016). As such, we ceased recruitment when it was considered that we had gathered in-depth information that provided an understanding of mothers' experiences (Guest et al., 2020).

Transcription was completed as soon as possible after each interview, either by the first author or using the online software, Rev computer. JD listened to the interviews and made any necessary amendments, including removal of all identifying features. This also provided an opportunity to develop familiarization with the data. Data was thematically analysed manually by JD using hard copy word documents following Braun and Clarke's six-phase process (Braun & Clarke, 2006). Thematic analysis is a method of analysing qualitative data which allows for the identification of common themes and patterns across data to explore meaning in people's experiences (Braun & Clarke, 2006). All transcripts were then read, and reflections were recorded. Initial analysis was used to shape ongoing data collection and refining of interview questions. JD then reviewed the transcripts to look for common patterns. After reading transcripts, JD developed initial codes and a codebook was completed. A selection of transcripts was then reviewed by MO and GH. Codes were then discussed amongst the authors and any disagreements were discussed until consensus was reached. JD then read all transcripts to generate, name and define themes (Braun & Clarke, 2006).

Quality

The guidelines for Consolidated Criteria for Reporting Qualitative Research were followed to ensure quality and rigour (Johnson, et al., 2020; Tong et al., 2007). To ensure rigour, JD kept a reflective journal to record thoughts and responses to data to enable awareness of personal reactions/bias and self-appraisal of positionality (Berger, 2013). Logs were kept including information pertaining to decisions made in response to the data, changes made to the study protocol and amendments to interview processes. An audit trail was kept to maintain dependability and confirmability; this included information regarding decisions made in relation to coding (Johnson et al., 2020). To ensure credibility, themes and brief descriptions were sent to a selection of participants with a request to provide feedback (Morse, 2015; Tong et al., 2007). Three participants responded and indicated that the themes were an accurate reflection of their experiences.

Findings

A total of 13 mothers, whose ages ranged from 28 to 37 years, were interviewed. Eleven mothers were between 4 and 39-week gestation at the time of their child's cancer diagnosis, and two mothers became pregnant while their child was in treatment. All women had given birth before being interviewed for this study. At the time of our study, seven children were currently in active treatment, with six having completed treatment in the previous 12 months. All children who had completed treatment were being regularly monitored by oncology departments for recurrence. On average, children had been in treatment for 15 months (range from four to 32 months). Seven of the children were male and six were female. The age of children with cancer at diagnosis ranged from 12 months to four years. The diagnosis varied with eight haematological, three neuroblastoma, one sarcoma and one lymphoma. Participants were recruited from all states in Australia. Interview length ranged from 62 to 95 mins. Ten participants identified their ethnicity as Australian, two as British and one as African.

Six themes were identified, which were (1) an impossible balancing act, (2) mother's health and well-being, (3) creating certainty: birthing plans, (4) a bit of sunshine and a time to rest, (5) challenges of caring for the baby and (6) unenviable position: doing my best versus feeling guilty.

An Impossible Balancing Act

This theme describes mothers' struggles with balancing being pregnant or having a baby and having a child diagnosed with cancer. Mothers recounted being scared about their ability to manage the dual roles of being a mother to a child with cancer and having a baby as seen in this quote "I called my mum, I said, I don't think I can do it. I don't want this … I didn't think I was going to be able to cope." Many mothers reflected that they were very fearful, as one mother recounted "I cried and cried. And I was like, how am I going to manage being pregnant and dealing with [my child diagnosed with cancer] treatment?" The child's cancer diagnosis changed mothers' vision of their lives, and some mothers appeared to find it difficult to adjust to the new reality of having a child with cancer and being pregnant at the same time. The diagnosis disrupted the vision of what their lives would be like:

> My thoughts went to, I wish I wasn't pregnant. I was in survival mode … I had this picture that our lives were going to be in the hospital [oncology ward]. I couldn't picture a baby. I went from being so happy … probably the happiest I'd been ever in my life … to fear

Most mothers explained that being pregnant and a mother to a child with cancer was challenging and that ultimately when having to choose where to focus their energy they focused on the child with cancer with one mother recalling "my child with cancer was the priority … saving his life was the only thing I could think about." Another commented, "pregnancy … was just another medical situation that needed to be managed really … get through … it just became the backseat issue very much, as opposed to the centre". Mothers focused on the child with cancer rather than the unborn baby with one mum describing, "there was about a week after [child] was diagnosed where I couldn't have told you even though I was very heavily pregnant if the baby moved." Thus, mothers' experiences of being pregnant were profoundly distorted by having a child with cancer, and their child's cancer treatment became their main focus. This struggle between competing demands continued beyond the birth of the baby, and mothers often had to make difficult choices between the baby and the child with cancer:

> How do you support a two-year-old with cancer, with a ten-week-old... with no support myself? Well, the nurses will help you. Well, no they won't, because what I really need is someone to hold the baby to sleep for an hour. It was just an utter disaster, trying to juggle the two babies … It's still one of the hardest experiences of my life, is leaving [baby] with other people just so I could have a couple of hours with [my child diagnosed with cancer] … It was like being ripped in two. It's been like that so often, which child needs me most.

The choice between being with their child with cancer or the baby was a source of anxiety:

> Look, it's like, you know that whole phrase drawn and quartered? … I wasn't going to be put in this impossible situation of which child am I staying with. You don't want your child cut open and left in the ICU without you, but also the ICU is really no place for a baby.

Therefore, mothers were frequently placed in a position where they had to choose between two children, each requiring high levels of care. In most cases, mothers felt that the child with cancer needed them most, with one mother describing "it wasn't really a choice … I knew the [baby] would be ok with [my mother] …my place was to be with [my child diagnosed with cancer] … but it broke my heart." It appears that the decisions they had to make while pregnant and after the baby was born left mothers feeling very distressed.

Mothers' Health and Well-Being

This theme explores mothers' health and wellbeing during pregnancy. It encompasses mothers' ability to obtain both normal self-care and antenatal care, and the additional risks pregnant mothers are exposed to during their child's cancer treatment. Mothers highlighted that they often prioritized the child with cancer rather than their care, and participants acknowledged that they did not take care of their health while they were pregnant. One mother stated this was a "fairly normal role of mothers to put children first." but that caring for a child with cancer intensified this 'normal' pattern of not taking care of themselves seen in one mother's quote "I think as a mum in general, your self-care goes out the window because you're so busy prioritizing your children all the time, and then when they're so very very sick, even more so." Another commented, "there was just no time to think about my care … when I was fighting to keep my child alive." Some mothers recognized the impact of their child's cancer treatment on their health:

> I was quite fit during the other half of the pregnancy as well, but I sort of deteriorated fitness-wise and motivation-wise quite quickly once she was diagnosed health-wise … I definitely know there were many times I had fruit toast for dinner because there was nothing else.

Issues of self-care were particularly evident in relation to healthy eating "I couldn't eat as well as I would have liked to because I was stuck in the ward or in clinic or whatever. My diet was atrocious." Basic nutrition did not occur with one mother recalling being asked by a health professional "Have you eaten any vegetables? I was like, (laugh) of course I haven't eaten vegetables." This sometimes resulted in health issues, for example, "I was very constipated. I got like the hacks inside of my mouth" Many mothers highlighted that the hospital did not provide any meals to mothers, and they lived off fast food "they don't provide food, they don't provide meals for the parents or anything like that … I just lived on chips from café." This reliance on fast food was common as a result of the practical challenges of living on the ward with limited access to healthy options.

This difficulty in taking care of themselves while their child was in treatment impacted all facets of their health care and well-being. Routine care such as adequate sleep, exercise and being in sunlight was difficult for some mothers "I just sat in a chair for all those last months of pregnancy … I was so unfit by the time I gave birth, and I don't think I saw sunlight for months ... because I was in with [child diagnosed with cancer] ... I just didn't go outside." Sleeping in the hospital either in bed with their children or lounge bed also made it difficult for mothers to get comfortable, "I got in pain. Sleeping on that hard, half a couch thing. I even tried sleeping in the recliner, and I got so much pelvic pain, back pain that I was administered codeine from my doctor." Another recalled, "the [baby] was transverse, so I was in a lot of pain … my hips burning in that hospital bed. Not being able to move because it's so thin, but he just wouldn't sleep unless I was right next to him." As such, the experience of having a child with cancer whilst being pregnant adversely affected mothers' health and wellbeing in a variety of domains. The additional healthcare needs of pregnancy were also often not possible, given the practical demands of caring for the child meaning that their pregnancy health and thus that of their unborn child was sometimes ignored. Some mothers also reported difficulties in attending all their antenatal appointments because of the need to be with the child with cancer, "I didn't always because even just getting into my routine maternity appointments was a nightmare because [husband] was at work and I couldn't leave [my child diagnosed with cancer] unattended on the ward … it was a nightmare." This continued after the birth of their child with several indicating they had not prioritized post-natal appointments or found alternative ways of getting check-ups, "I think I just cruised along. I don't even know. I didn't attend my appointments." This inability to focus on their healthcare continued beyond the birth of their baby and can be seen to impact their recovery from birth:

> So, I stumbled my way over from maternity hospital less than 48 hours after I had [baby] because [my child diagnosed with cancer] was in hospital having Doxorubicin for the first time ... We had been warned that was probably going to be pretty hard for him … I was just deadly intent on the need to get back to [my child diagnosed with cancer].

Mothers highlighted the additional healthcare risk that pregnant mothers faced of being exposed to chemotherapy. Mothers described having to care for their child with cancer including changing nappies and cleaning up vomit that were "cytotoxic" [anti-cancer medicines that contain chemicals that are toxic to cells, preventing their replication or growth] as a result of the chemotherapy that their child was receiving to save their lives. The cytotoxic nature of chemotherapy and the risk to their unborn children was raised by some mothers as an area of concern. One mother who was 22 weeks pregnant commented:

> When he was in ICU, they had a couple of pregnant nurses looking after [my child diagnosed with cancer] that they rotated them out, so no pregnant nurses were allowed to look after him. I was like, Gosh, that's crazy. I'm pregnant. What does that mean for me? They just said, just be really careful with your hand hygiene and gloves and things.

Caring for a child with cancer meant that exposure was often inevitable, "I just found out that I was pregnant, while he was in for his treatment. And then he vomited all over me while having his chemo. So that was like, … I've got to get changed. Like, I have no other clothes and I'm covered in vomit when he has just had chemo". While mothers acknowledged the risk and felt concerned, most just accepted this risk, "They pretty much said if you're pregnant, don't deal with it, but I didn't really have an option because most of the time that was only me that was there that was able to do that. So … I just wear the gloves, deal with the chemotherapy risk." Another commented, "I think I'm a bit blasé sometimes about that stuff … It is what it is … I'm not going to not help my child just because I'm pregnant." Many mothers adopted a pragmatic approach to this risk from exposure to cytotoxic treatments, accepting that they had little choice.

Birthing Plans: Creating Certainty

This theme explores mothers' decisions to alter their birthing plans to accommodate their child's cancer treatment. Almost all mothers indicated they amended their birthing plans and/or location to accommodate their child's cancer treatment schedule. Several mothers had elective caesarean sections to fit in with their child's cancer treatment with one mother explaining her decision:

> We decided that we were just going to have a scheduled C-section for the baby … It was just a way of creating a bit more certainty around the situation, and also it gave us an opportunity to make sure that we could get the stem cells for potentially using in the future. In my mind, it was more, hopefully creating more predictability around what the outcome of the birth would be.

Changing birth plans was a logical process and the risk of an unpredictable birth appeared to impossible to contemplate. One mother remarked, "I could never let that go natural … There was so much going on with [my child diagnosed with cancer] and her treatment." Adjusting plans seems to have given mothers comfort and provided them with the ability to focus on the child with cancer. Another described "I couldn't deal with any more uncertainty. I just wanted to plan his birth around her chemo … as soon as I heard about that I elected to have a caesarean." A few mothers also outlined changing hospitals to fit in with their child's treatment:

> I swapped hospitals to be closer to the children's hospital because I didn't know how I would be and how she'd be with her chemotherapy. I just wanted to be in the next hospital from her in case my husband and family members had to go back and forth. Or something happened with the baby and the baby was born early, because that was another concern. Everybody was worried that my son was going to be born early, premature because I was under such high stress. I just wanted to be at the hospital.

Several mothers had planned inductions so that the birth could fit in with the chemotherapy treatment; one mother explained, "We were having to be admitted for five days, and there was one week on, one week off. On my week off, I had to be induced to have [the baby], because otherwise, I could have gone full term." Changes to birth plans appeared to have afforded mothers a greater sense of control and certainty, during a chaotic time and may have also served to alleviate feelings of conflict between the needs of their child with cancer and their unborn child.

A Bit of Sunshine and a Time to Rest

This theme describes mothers' descriptions of the birth of their baby. While mothers acknowledged the stress of being pregnant while their children received treatment for cancer, most mothers felt that the birth itself was a positive experience and they focused on the happiness it brought:

> It was so nice. It was such a beautiful experience in comparison to what we were going through. It was lovely… it is nice to focus on something positive at that time … He [baby] just gave us all something really lovely to focus on, something normal.

The majority of mothers reported that the obstetricians and midwifery staff were supportive and created a safe environment, "I was in a nice little bubble in the hospital." While many described being fearful of their ability to care for both the child with cancer and the baby, the joys of a baby also provided a welcome positive in a difficult time "She's definitely added that bit of sunshine that we needed" and "Babies do bring a lot of joy and positivity to families. I think she has been a blessing." The joy of having a baby was for most mothers a break from the stress when they allowed themselves to focus on the baby rather than the child with cancer. This provided mothers with a break from the trauma of caring for a child with cancer, "it was a little holiday from the ward." It also appears to have provided them with an opportunity for their health to be taken care of, "It was kind of nice really, someone was bringing me food and asking if I was ok … that never happened in the oncology ward … in that way, it was such a nice time." Despite the immense stress of caring for a child with cancer, the birth of a new child was a moment of respite in which mothers could regain some sense of normalcy.

Challenges of Caring for the Baby

This theme explores the difficulty mothers faced in caring for a baby and caring for a child with cancer. Some mothers indicated they tried to care for the baby and their child with cancer in the ward, but this posed many practical challenges: "the only place to change your baby is a public bathroom in a hospital, which is not ideal for a baby because the chemo bathrooms are for the chemo patients ... I understand that ... but you didn't know what you were going to expose your baby too." A baby's demand for care did not align with life on the ward "I think when she was 10 days old, I tried to stay in the hospital with her and [my child diagnosed with cancer] one night, it was just a disaster. She was crying all night." The challenge of caring for a baby and a child with cancer were particularly difficult for those who had limited family support or were single mothers. One mother who had no one to care for the baby recalled the struggles of attending to a child receiving chemotherapy and a baby "I worked out that I can hold the baby in one hand, and just try … [to clear up vomit], or just quickly lay the baby in the bassinet, and run around like a headless chicken, and fix up [my child diagnosed with cancer] giving him what he needed."

Breastfeeding was an area of concern for some mothers, and they discussed the demands of feeding a baby while caring for a child with cancer. This is highlighted in one mother's comments:

> It was just so hard because trying to have a baby on your boob, while you're trying to deal with [my child diagnosed with cancer] at the same time. Then I tried pumping, while the kids are asleep in their beds at the hospital, but even that just got too hard. You're just so so exhausted.

Another commented "Yes, I breastfed, it was difficult because we had long days at the hospital and having a baby and breastfeeding is not easy when you're in a hospital environment ... there is no privacy, and it is hard to care for a child who is so ill throwing up and in so much pain when you are holding a baby." Several mothers commented that they ceased breastfeeding early due to the demands of caring for their child with cancer. This was difficult for many mothers, and they described feeling sadness "I was breastfeeding for four months but … [baby], eventually just stopped taking the boob, because I wasn't around. That was heartbreaking as well … I exclusively breastfed the others." The decision to stop breastfeeding often was not a choice and one that brought deep regret "it wasn't the plan. I fed [my child diagnosed with cancer] until she was 18 months, and I was hoping to do the same with him, but I think with me not being there being able to feed and stress, my supply … So, I lost that … that was hard." When questioned about the support provided, most mothers indicated that due to their child's cancer treatment and the practical elements of being in the ward with their child with cancer, they were not able to access many of the normal supports to continue breastfeeding. One mother observed that it would be beneficial to have "a lactation consultant to come in and see you", describing how getting away from the hospital to see a consultant was "completely impossible." Breastfeeding was an emotional issue for mothers as the decision to continue breastfeeding brought with it numerous challenges, and for many mothers, breastfeeding was not a viable option. Often, this conflicted with mothers' plans and expectations of caring for their baby and was a source of distress.

This balancing act of caring for two children with high care needs sometimes meant that the baby did not receive the routine healthcare that is expected after birth. One mother recalled, "I didn't really take (baby) to any of the … check-ups because I felt I couldn't do that. There wasn't a way of fitting it into the life that I was living at the time." The child with cancer's neutropenic status also impacted the care of the baby with one mum recalling:

> the fact that I was unlikely to present at any of those clinics where you go and weigh baby … I don't think I would have gone as I was avoiding people ... So that was when [my child diagnosed with cancer] was neutropenic … so, I stood on the scales with [baby] and then step off without her and see that she had put on weight … I probably wasn't the most dedicated new mother.

The role of caring for two children was difficult. and the focus tended to be on the child with cancer, with the baby care fitting in to accommodate the child with cancer:

> I knew [baby] would be okay…she just tagged along for the ride that she was always there. I always made sure someone took care of her, that she was ok, it was just at that [baby] didn't do normal baby, stuff … go to music, baby class or whatever. She went to the oncology department. That was her outing … she just had to get on with it. … I didn't have a mother's group, but I kind of didn't want one either that I

> would think I just had the mental capacity to do that instead of going to the mother's group, we went to the cancer ward.

Unenviable Position: Doing My Best versus Feeling Guilty

This theme focuses on mothers' emotions regarding the choices they had to make between the child with cancer and the baby and how it impacted their perceptions of their role as mothers. There was variation between mothers regarding feelings, with some mothers approaching the situation in a very pragmatic way. One mother explained that while she knew that pregnancy care was important, "quite frankly I couldn't be in two places at once [attending midwifery appointments] … I was doing what I had to do." Some mothers described not allowing themselves to feel guilty, explaining that they knew they were in a difficult position "I felt like I just had to do the best thing that I could in the situation, because if I started to be a martyr and beat myself up over the situation. Then that was going to upset me and make me less capable of looking after them."

In contrast, the balancing act between focusing on the pregnancy/baby or the child with cancer left some mothers feeling guilty. One mother recalled worrying about how the life she led [on the ward] and "not doing the right thing [in relation to healthcare]" would impact the baby "sometimes ... in the middle of the night when the baby was kicking, I would worry." The situation caused some mothers to question their mothering "I constantly question whether I'm doing the right thing. I have a lot of guilt. With my son and with [baby] whether or not I've given them the time that they needed and also whether I am doing a good job as a mum." Not being able to provide the 'normal' care for the baby resulted in guilt seen in this quote:

> I didn't really feel the need to weigh her and do all of that stuff like I did with [my child diagnosed with cancer] … but then I do remember feeling very guilty about that, but I would have preferred to get more support to do that … but it just seemed to be out of reach to try doing that.

One mother who reported having little support described that the baby had grown up in the ward, and now as a toddler often had to be confined to the pram while the older sibling with cancer received treatment in the clinic:

> I feel like I failed him. He shows some delay because you can't bring all his toys. You can't bring everything from home … I see him compared to the other two-year old's now, you can see the delay in him … He gets bored, very bored … when he's confined in the pram.

In this instance, the mother felt conflicted that the treatment required for the child with cancer had negative impacts on her other child, influencing her view of herself and her role as a 'good mother'.

Discussion

Our study explored the experiences of mothers who were pregnant or had a baby while their child was receiving treatment for cancer. Findings demonstrated that mothers of children who have been diagnosed with cancer face not only the typical challenges and stress of having a child receiving treatment, but also encounter many additional challenges due to their pregnancy that adversely impact their physical and emotional well-being. Studies have demonstrated that mothers of children with cancer experience high levels of stress and anxiety while their child is in treatment (Alderfer et al., 2005; Klassen et al., 2008; Sulkers et al., 2014). Mothers also experience significant disruption to their self-value as 'competent mothers', and there is a need to put their own life on hold while caring for the child with cancer (McEvoy & Creaner, 2022). Cox (2016) contends that mothers of children with cancer need to develop a new way of living as cancer disrupts their sense of having a 'normal' life. In our study, mothers described that the stress of having a child with cancer was exacerbated by the demands of pregnancy. Mothers in this study found it difficult to juggle competing demands, and most mothers struggled to make decisions and create a new 'normal'.

Within our study, it is evident that mothers had to process the difference between their planned 'vision' and the reality of struggling to care for their unborn child and child with cancer. Bury's (1982) biographical disruption theory can be applied to help understand the impact of childhood cancer. Bury observes that all people tell stories about their lives and carry with them a personal life narrative and that when these narratives are disturbed due to illness, people are forced to examine and reconstruct their narratives to incorporate and make sense of the disruption. Young et al. (2002) contend that a child's cancer diagnosis results in 'biographical disruption' as mothers have to process a new vision of their role in caring for a child with cancer. They also argue that a child's cancer diagnosis challenges societal discourses around motherhood, challenging accepted roles and functions. In our study, we see that pregnant women do not only have a vision for the life of their child with cancer, but also their planned narrative for their pregnancy and the life of their unborn child and their mothering role. This appears to have posed many challenges for mothers and resulted in anxiety as they struggled to incorporate the new realities of being pregnant and having a child with cancer.

Reports have previously demonstrated that mothers of children with cancer often neglect their health while they care for their child with cancer (Fletcher & Clarke, 2003; Young et al., 2002). This study highlights that mothers who are pregnant also report that they have little opportunity to eat healthily, that exercise was limited, sleep was disturbed and that despite being pregnant they did not engage in self-care including routine pregnancy care. The demands of caring for their child with cancer and lack of organized support meant that many of these aspects were impossible to achieve as they focused their energy on caring for their child with cancer. Mothers also discussed how the physical demands of caring for a child with cancer impacted their physical health and resulted in increased discomfort and pain related to their pregnancy. Pregnancy health guidelines specify that it is important that pregnant women eat well, get regular exercise and have any specific healthcare needs met, and studies have demonstrated that antenatal interventions that support mothers to adopt healthy lifestyles are effective (Bahri Khomami et al., 2021). Our study shows that the healthcare system within children's hospitals to does little to assist pregnant mothers to get adequate healthcare.

Mothers in our study appear to have proactively taken charge of their birth plans to accommodate the needs of the child undergoing cancer treatment. This contrasts with a report by Kingdon et al. (2009) exploring decision-making around birth plans which found that mothers felt that choice over birth plans was important but that mothers were generally reluctant to express their wishes to make changes regarding birth timing and delivery method. During a time of vulnerability and stress, mothers were able to assert their needs including the need to prioritize the child with cancer. Obstetric services were typically accommodating and supportive of these birth options. While these birth options were necessary in the circumstances in order for mothers to accommodate the need of the child with cancer, some of these birth options such as induction of labour (IOL) can have negative implications including 'intervention cascade' with more medical interventions required after IOL (Coates et al., 2020). The 2014 research project undertaken by the WHO which aimed to optimize maternal care highlighted the need to identify aspects that disrupt the delivery of care (Kennedy et al., 2018). It would appear that given the need to adapt birth plans to fit in with childhood cancer treatment, there is a need for additional healthcare and monitoring provided to mothers of children with cancer to mitigate any potential negative impacts from changes to birth plans.

Our research is novel in describing the complexity of emotions that mothers feel in caring for their child and their baby. Previous research has described how mothers often feel conflicted in needing to be with their child with cancer but also feeling like they are 'neglecting' siblings (Young et al., 2002). For mothers who have a baby while their child is in treatment for cancer, these emotions are only intensified. Both the baby and the child with cancer have high care needs, and the current hospital structure appears to make it difficult for mothers to provide care to the child with cancer and the baby. Breastfeeding appears to be a particular issue. Mothers in the current study reported that they had the intention to continue to breastfeed, but that they had to cease breastfeeding due to the difficulty in juggling the demands of a child with cancer and the baby. There were multiple reasons for this including often being away from their baby (who was taken care of by the father or another relative at home), the practical difficulties of feeding in the ward with their child with cancer, and stress and trauma making supply difficult.

We found that post-birth mothers of children with cancer were generally not provided with the additional care they need in order to navigate the accumulative stressors of caring for a child with cancer as well as a baby. In our study, mothers reported having no time for rest, recovery, nurturing and bonding while trying to meet the needs of caring for a child with cancer. Given the growing awareness and research that shows that mothers require additional support and care during the 'fourth trimester' (the 12 weeks after birth) (Cornish & Dobie, 2018), our findings raise concerns regarding the long–term psychological and physical outcomes for these mothers. It is not uncommon for new mothers to neglect their well-being, and McCarter and MacLeod (2019) report that many mothers in the post-partum phase often 'sacrifice' their own care to care for their child. For mothers of children with cancer, this situation is magnified, and mothers outline how they have little time for completing routine post-partum care including attending routine medical appointments for both themselves and the baby. Research has highlighted that in the fourth-trimester, mothers require individualized care that accommodates their particular circumstances (Tully et al., 2017). Our study has identified a potential gap in addressing the additional needs of a pregnant mother whose child is receiving treatment for cancer and the need for improved access to support and healthcare (Homer, 2016).

The majority of mothers in our study were not provided with any psychological support to manage the stress of having a child with cancer whilst being pregnant or the complexity of managing these two roles. This is concerning since stress has been shown to have a negative impact on pregnant mothers including increasing the risk of low birth weight (Hamada & Matthews, 2019; Poston et al., 2011). Kennedy et al. (2018) argue that improving the support provided to pregnant mothers has the potential to improve psychological outcomes for both mothers and their children.

Limitations and Future Research

The major limitation of our study is that convenience sampling may have resulted in self-selection bias as those mothers who encounter issues during their pregnancy may have volunteered to participate and share their experiences. Snowball sampling was used to address this particular limitation, and five participants were recruited through this method. Another limitation of our study is that participants were all from English-speaking backgrounds. This is a common problem in qualitative research. Attempts were made to address this problem via purposive sampling; however, no participants from culturally and linguistically diverse (CALD) backgrounds were recruited. There were also no participants who identified as Aboriginal or Torres Strait Islander. Further research on the experiences of mothers who are pregnant and from CALD and Indigenous backgrounds is warranted. Finally, it was not within the scope of our study to collect data on mothers' physical well-being. Mothers reported poorer health and a lack of self-care during their pregnancy, and data on this would be beneficial in future studies.

Clinical Implications

Whilst the stress of having a child with cancer is inevitable, measures could be put in place to mitigate the additional impact of pregnancy via appropriate psychological support and midwifery support. One of the key recommendations of this study is to implement a system where healthcare providers identify pregnant women as mothers who need additional support. Mothers require a thorough assessment of their current health and psychological support needs while their child is in treatment for cancer. There is a need for a more family-centred holistic approach that increases access to services in flexible and appropriate methods. There should be a particular focus on continuity of care utilizing midwifery services within the hospital or home to improve access and reduce time commitment for mothers of children with cancer (Homer, 2016; O'Brien et al., 2021).

Our study has identified some potential in our health system for pregnant or nursing mothers caring for children with cancer in the hospital that warrant more in-depth exploration. Firstly, mothers in our study discussed difficulties with accessing healthy dietary options whilst staying in the hospital with their child. Given the nutritional requirements of pregnancy, all pregnant and lactating mothers should routinely be offered regular meals from hospital catering that meet the specific requirements of pregnancy. Additionally, mothers also raised pelvic pain and issues regarding sleeping in hospital wards, and this finding potentially warrants the introduction of changes in hospital facilities to accommodate pregnant mothers.

Numerous guidelines underscore the importance of breastfeeding in determining child health outcomes and assisting in maternal recovery (McFadden et al., 2017). We suggest that mothers are provided with lactation consultants either within the hospital or at home to support them to continue breastfeeding where possible. While our study focused on families in Australia, it is estimated that every year globally 397,000 children between 0–19 will be diagnosed with cancer (Ward et al., 2019). The clinical implications outlined here would be relevant in paediatric oncology settings in other countries. Finally, our study has focused primarily on mothers whose older children were being treated for cancer; additional longitudinal research is warranted on the long-term impact on the infants regarding physical health and development. These measures have the potential for significant improvement in care for families, particularly mothers and also reduction in costs to the healthcare system overall by reducing long-term negative impacts for the mother and the unborn child.

Conclusion

Our study provides a rich understanding of the experiences of mothers who are pregnant while their children are receiving treatment for cancer. Previous studies have highlighted the burden that mothers experience when their children have cancer. We have expanded on this knowledge to show the additional challenges faced by mothers who are pregnant while their children are receiving treatment for cancer. These mothers require the development of a comprehensive and coordinated program that identifies these mothers at the beginning of their child's treatment and provides them with holistic care which focuses on their physical health and well-being and that of the unborn child.

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Ethical Approval

Our study was approved by Curtin University Research Ethics Committee (HRE2021-0119). All participants provided written informed consent prior to enrolment in the study.

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Appendix

Interview Guide

At the commencement of the interview, participants will be provided with a brief overview of the study and ethical considerations explained including a brief review of consent process and right to withdraw. The suggested example follow-up questions will only be used in response to appropriate responses from interviewees.

Q1 Can you describe your feelings and emotions regarding your pregnancy when your child was being treated for cancer interviewer?

Q2 Can you describe what your self-care and pregnancy care was like while your child was in treatment for cancer?

Suggested example follow-up.

How was your sleeping and eating while your child was in treatment?

How did you manage normal pregnancy health/comfort issues?

Did you attend all the routine pregnancy care?

Q3 Could you describe your experiences of birth while your child was in treatment?

Q4 Could you describe what it was like caring for the baby and having a child in treatment for cancer

Suggested example follow-up.

What was your breastfeeding experience while your child was in treatment?

Q5 What support did you receive while you were pregnant and had a child in treatment?

Clinical recommendations

While the stress of having a child with cancer is inevitable, measures could be put in place to mitigate the additional impact of pregnancy via appropriate psychological support and midwifery support. While there is obviously a cost involved in delivery of these services it is essential for both the health of the mother and the unborn child that there is an improvement in services delivered to pregnant mothers of children with cancer. These include:

- Pregnant mothers require a thorough assessment of their current health and psychological support needs when their child is diagnosed with cancer.
- Health care systems need to provide pregnant and lactating mothers with healthy meals that meet their specific pregnancy nutritional needs.
- There should be a particular focus on continuity of care, utilizing existing community midwifery services to attend to mothers within the children's hospital to improve access and reduce the time commitment for mothers of children with cancer.
- Mothers raised issues with pelvic pain and sleeping in hospital wards, and this finding warrants the introduction of changes in hospital facilities to accommodate pregnant mothers, including pregnancy physiotherapy services.
- Lactation consultants need to be provided in the hospital to support mothers to continue breastfeeding where possible.
- Facilities and supports need to be provided in children's hospitals to assist mothers to care for newborns on the wards. There is also a need for additional healthcare and monitoring to be provided to mothers of children with cancer to mitigate any potential negative impacts from changes to their birth plans.

- Longitudinally assessments to be completed for both the mother and the unborn child to assess the impact of the child’s cancer diagnosis on their health and well-being.

CHAPTER 6 - Study 4: Grandparents' experiences of childhood cancer: A qualitative study

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Chapter overview

This chapter consists of the fourth published study of this thesis. The aim of this study was to explore the experiences of grandparents of children diagnosed with cancer. Grandparents were interviewed and invited to discuss what it felt like having a grandchild diagnosed with cancer. Grandparents were recruited from across Australia via social media posts and flyers distributed via support organisations. The sample consisted of twenty grandparents (thirteen grandmothers and seven grandfathers). Data was analysed using reflexive thematic analysis and Braun and Clarke's six phase process. Five themes were found. This study was published in November 2023 in the *Journal of Family Nursing*, a peer reviewed journal which covers the topics of nursing research, practice, education, and policy issues in relation to family health (Davies et al., 2023).

What this adds to the literature

This study illustrates the profound and transformative effects experienced by grandparents when their grandchild is diagnosed with cancer. It reveals that for some grandparents' changes in workforce demographics means that grandparents are now more likely to be in the workforce and are thus required to juggle both caring for their adult children/grandchildren and the demands of paid work. This created additional stress which has not been explored extensively in previous research. An additional novel finding of this study is that many grandparents find themselves “sandwiched” between having to care not only for their adult children and their grandchildren with cancer, but also for their elderly parents. This burden created stress and anxiety for grandparents as they felt squeezed between competing demands. These findings reflect changing demographics within society and the need to be aware of these issues when providing support to families and grandparents of children with cancer.

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Research

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Grandparents' Experiences of Childhood Cancer: A Qualitative Study

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Abstract

A child's cancer diagnosis has a significant impact on the lives of grandparents. Grandparents experience the stress of worrying about both their adult children and their grandchildren. Our study aimed to explore the lived experience of grandparents of children diagnosed with cancer. A qualitative design involving semi-structured interviews was used and data were analyzed using reflexive thematic analysis. Twenty grandparents aged 41 to 77 years were interviewed. Six themes were identified: (a) Diagnosis: changing everything; (b) Aspects of treatment: A different world; (c) Sandwich generation; (d) Family: Worrying about everyone; (e) Balancing work; and (f) It's like suddenly a door opens. Our study demonstrates the life-changing impact of having a grandchild diagnosed with cancer. It expands on existing knowledge and shows that, due to an aging population and demographic changes, some grandparents must juggle the demands of caring for aging family members and working while supporting adult children and grandchildren.

Keywords

oncology, cancer, grandparents, qualitative, family, siblings

The diagnosis of childhood cancer is a life-changing event that profoundly affects both the child and their family members (Kearney et al., 2015). Due to the complexities of treatment, families need to alter many aspects of their lives to accommodate treatments and care for a child with cancer (Wakefield et al., 2014a). Grandparents often play a pivotal role when a child is diagnosed with cancer, taking on additional responsibilities, and in some cases, moving in with the family to care for siblings and providing care for the child in the hospital (Kelada et al., 2019; Wakefield et al., 2014a, 2017).

These additional responsibilities significantly disrupt grandparents "normal" life (Moules et al., 2012b). Wakefield et al. (2017) found that grandparents experience a lower quality of life (QOL) and lower physical health compared with controls and have higher rates of depression, anger, and anxiety. Many grandparents also have their own health conditions which can impact how they manage the changes in lifestyle (Wakefield et al., 2014a).

Grandparents' experiences have been described as "double grief," worrying about their grandchild diagnosed with cancer (GDWC) and their adult children (AC) (Hall, 2004; Moules et al., 2012a). Family communication changes after a child is diagnosed with cancer and grandparents must negotiate the complexity of their new roles (Wakefield et al., 2014b). Moreover, as their focus is on caring for their AC (the parents of the child with cancer) and their grandchildren, grandparents have revealed that they cannot express their distress as they are reluctant to place additional burdens on their AC (Charlebois & Bouchard, 2007; Moules et al., 2012a; Wakefield et al., 2014b). Grandparents have also been found to have concerns about the information provided to them related to their grandchildren's cancer (Wakefield et al., 2014b). Grandparents reported that they needed more direct

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information from health care professionals (HCP) so they would not have to rely on parents for information (Findler, 2014; Moules et al., 2012b; Wakefield et al., 2014b).

Much of the research on childhood cancer focuses on the impact on the nuclear family, and there are limited qualitative studies that have examined the experiences of grandparents of children with cancer (Findler, 2014). There is a need to further explore grandparents' experiences of childhood cancer to gain a better understanding of how the cancer diagnosis and treatment of their grandchild impacts their lives (Charlebois & Bouchard, 2007; Moules, et al., 2012a; Wakefield et al., 2014a, 2017). This must include a specific focus on how changing demographics have impacted their experiences. In this study, we aimed to explore the lived experience of grandparents of children diagnosed with cancer.

Research Design

The hermeneutic phenomenological approach was used to explore what people "think" about their experiences (Wojnar & Swanson, 2007). This approach was chosen as it aims to develop insight into how people make meaning from their experiences, with a focus on capturing "what it [is] like" to be a grandparent of a child with cancer (Eddles-Hirsch, 2015). We used a qualitative method involving interviews of grandparents as it recognizes the importance of individuals' experiences being described in their own words (Denzin & Lincoln, 2013). Semi-structured interviews were used, enabling a more natural form of communication and allowing for the gathering of clear information regarding how participants felt about their experiences (Leavy, 2017).

In this study, we were informed by ecological systems theory. This theory posits that a person's well-being is dependent on interrelated and complex factors within the social system within which they are situated (Bronfenbrenner, 1979). It emphasizes the interconnectedness of people and that the well-being of one person affects others (Murrell, 1978). Ecological systems theory provides a conceptual framework for articulating the necessity to look at the context surrounding the child and highlights the need for analysis of childhood cancer to include an examination of those who are proximal to the child, such as parents and extended family including grandparents (Darling, 2007; Murrell, 1978).

We conducted this study in accordance with ethics approval attained through the Curtin Human Research Ethics Committee (HRE2021-0119) in March 2021.

Recruitment and Procedure

Participants were drawn from various childhood cancer networks throughout Australia. They were initially recruited by convenience sampling as the population is small and recruitment can be difficult. We then moved to purposive sampling to reach participants from different groups, including grandparents whose grandchildren had received varying cancer diagnoses. Recruitment notices were placed on closed oncology families' Facebook pages. Access to these closed groups was facilitated by (JD's) status as an insider researcher and a parent of a child who was diagnosed with cancer. Childhood cancer organizations also assisted by placement of recruitment notices on social media. We also used snowball sampling, whereby initial participants were asked to nominate other eligible participants (Parker et al., 2019).

Inclusion/Exclusion Criteria

Participants were grandparents whose grandchild was 17 years or younger and who were currently receiving or had completed cancer treatment within the previous 15 months. Adults who functioned in the role of grandparent were included. Both biological and step-grandparents and multiple grandparents from the same family were included. Bereaved grandparents were ineligible for our study.

Data Collection

Interviews were conducted by (JD), either by video teleconferencing (Teams or Zoom) or at a location suitable to participants between August 2021 and December 2021. Audio recordings of the interviews were made with a digital recorder. Before the interview, all participants were given a study participant information sheet, a consent form, and a demographic questionnaire which included participants' education levels, ethnicity, and work status. We used a flexible interview guide to inform the interview process; an example of an interview question is "How has your grandchild's cancer diagnosis impacted your family roles and responsibilities?" Prompt questions were also used to elicit further information. We developed interview questions from a review of previous research and consultation with consumer representatives. A preliminary analysis of initial interviews was also used to refine questions with minor amendments made to prompt questions. At the commencement of the interview, (JD) provided a summary of the research topic before confirming the participant had read and understood the participant information sheet. Consent to audio-record the interview was sought. We provided participants with options to cease/pause the interview. Participants were given support services details and offered a $20 gift card as an honorarium.

We continued recruitment until it was deemed that the data being analyzed contained an in-depth exploration of participants' experiences. Data collection can never be "complete," and qualitative research seeks to obtain rich data that achieves an in-depth understanding (Guest et al., 2020). We relied on the concept of information power, which outlines that the more in-depth and richer the data, the fewer the number of participants needed (Malterud et al., 2016). As such, we ceased recruitment when it was believed that in-depth and rich information had been provided (Guest et al., 2020).

Data Analysis

We conducted data collection and thematic analysis concurrently (Braun & Clarke, 2019). We completed transcription as soon as possible after each interview via the online transcription service rev.com, or manually by (JD). All interviews were transcribed verbatim, and all individual identifiers were removed. Data were analyzed using Braun and Clarke's six-phase reflexive thematic analysis process (Braun & Clarke, 2019). First, we sought to develop familiarization and immersion with the data, so after transcription, all interviews were listened to by (JD; with any necessary amendments made to transcripts for accuracy). The transcripts were then read and re-read by (JD) to look for common patterns, and notes completed on initial responses. Second, after reading transcripts, codes were developed using a manual paper-based process with codes attached in the margins. The third phase involved codes being reviewed and analyzed by (JD) to develop initial themes across the data. The fourth phase involved the development and review of themes by all authors. To assist in the fourth phase, a thematic map was developed to graphically represent findings and review themes. In the fifth phase, themes were reviewed and revised by all authors to ensure unnecessary themes were excluded, and names were given to each theme. Finally, themes were converted into a report by (JD) and this was reviewed by all authors.

The guidelines for Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed to ensure quality and rigor (Tong et al., 2007). As outlined by Braun and Clarke (2019), the reflexive approach aims to acknowledge the researcher's active role in interpreting data, and during the process, the researchers were aware of their reflexive responses. As an insider researcher, (JD) was mindful to reflect on their experiences and how this impacted the research. (JD) kept a reflexive journal to record personal observations (Braun & Clarke, 2020). During the research process, (JD) also kept logs of research decisions and modifications to the research protocol. This measure aimed to improve the dependability of the research process (Johnson et al., 2020; Tong et al., 2007). We consulted with two consumer representatives who were grandparents with lived experience as grandparents of a child with cancer. They provided direct input on research methods and provided input on interview questions and forms to ensure the study materials were easy to understand. Involving consumers ensures that the research is inclusive and designed to appropriately reflect participants' views (Happell & Roper, 2007). To achieve member checking, we also randomly selected seven participants and emailed them an overview of the final themes (Happell & Roper, 2007). Five participants provided feedback that the themes were an accurate reflection of their experiences. Two participants did not respond to the email. These measures in combination ensured that the analysis was credible, transferable, confirmable, and dependable (Johnson et al., 2020).

Research Findings

A total of 20 grandparents—13 grandmothers (GM) and 7 grandfathers (GF)—were interviewed as part of our study. Grandparents were aged between 41 and 77 (median=65 years, *SD*=9). Fifteen grandparents were still working either part-time or full-time and 5 were retired. The interviews were completed either face-to-face (10) or via teleconferencing (10). Each interview was on average 61 min long (35–79 min). Additional demographic details are provided in Table 1.

Themes

Six major themes were identified (listed below). Due to the complexity of human emotions, there are some overlaps between themes, but all outline specific aspects of grandparents' lived experiences.

Diagnosis: Changing Everything. This theme captured the grandparents' reactions and feelings about hearing about their grandchild's cancer diagnosis. Many grandparents described it as a shocking and life-changing moment, saying that "the minute they said oncology . . . my heart sunk because I knew oncology is cancer . . . our whole life is going to change forever" (GM). Many grandparents explained that a child's cancer diagnosis was different to cancer they had experienced among adults, describing that having a child diagnosed with cancer "was wrong, so very wrong . . . it's different in adults to when it's children . . . Although you don't cope you cope a whole lot better when it's adults than when it's children" (GM). As one GF described:

> Everything is going to go in a natural process . . . I'm going to get old and die, and then my kids are going to get old. That suddenly being flipped around to this tiny, little baby who had only just started this life was suddenly faced with dying in front of us . . . this was just not how it's supposed to be. (GF)

Several participants also talked about how their grandchild's cancer threatened their ability to think about the future, as described by one grandparent who said, "My family wouldn't be complete without [GDWC] . . . how do [you] . . . think about future when such a precious child might not be part of it" (GM). Childhood cancer impacted not only the present but their ability to envision their families' future.

Aspects of Treatment: A Different World. This theme describes grandparents' responses to aspects of their grandchild's treatment.

Table 1. Sample Sociodemographics (N=20 Participants).

Demographics	N	%
Marital status		
Married	20	100
Educational		
Year 10 (age 15–16)	5	25
Year 12 (age 17–18	5	25
TAFE/local college[a]	1	5
Bachelor	5	25
Post-Graduate	4	20
Work status		
Retired	5	25
Full time	6	30
Part time	9	45
Changed work status		
Yes	7	35
No	13	65
Child's primary diagnosis		
Brain cancer	4	20
Sarcoma	2	10
Hematological	11	55
Other	3	15
Stayed in hospital overnight		
Yes	9	45
No	11	55
Ethnicity		
European	3	15
Australian	13	65
British	3	15
Asian[b]	1	4

[a]TAFE post high school non-compulsory vocational training. [b] Asian refers to participants who were born or descended from Northeast, Southern and Southeast Asian. Primarily China, India and the Philippines.

Sub-Theme: The Ward. This theme describes grandparents' responses to attending the ward and witnessing their grandchildren receiving treatment. Visiting the ward appears to have been extremely distressing, as highlighted by one grandparent saying, "Every time I went to the hospital, I'd get there and walk through the door and be sick in the toilet" (GM). The complexities of the ward were difficult for grandparents to process; one GF stated, "Being on the ward, that's an experience and half . . . with alarms going off all the time and the lines everywhere . . . and nurses changing this and that." This response was even more pronounced for those grandparents who were directly involved in assisting the parents to care for their grandchild on the ward. One grandparent stated, "I had to hold [GDWC] down a lot because mother of the child wasn't well enough . . . Holding her, knowing how scared she was and how angry she was with me" (GM). It appears that being directly involved with caring for the GDWC was emotionally distressing for grandparents, and while they stepped in to provide support, the experience came at a high cost for some grandparents.

Sub-Theme: Hyperalert—Keeping Your Grandchild Safe. This theme reflects grandparents' concerns regarding their grandchild's risk of infection. Many grandparents, particularly those who spent time on the ward, noted that they were fearful of spreading an infection to their grandchild. One GM described that "I would go home [from the ward] and think, 'Oh my god I've got a sore throat now . . . he is going to catch something, and he is going to die and it's going to be my fault." This fear of infection resulted in grandparents adjusting their lifestyle to reduce risk to their grandchildren; for example, one GM described arrangements where, "if my husband's sick, I move into the front of the house. He stays at the back of the house so that I'm less likely to get sick so that I can continue to . . . provide support." Another GM described how continuing to work posed additional challenges:

> Another staff member was coughing so I just . . . showed her a photo of [GDWC] . . . and just said "have you got a cold?" . . . and explained to her if they have a cold and I catch it and go and see [GDWC] I can kill her. (GM)

Fear of infection impacted all aspects of their life: one grandparent said, "We're very conscious of not being very social . . . and collecting germs to take to the hospital" (GF). In these quotes, it is evident that childhood cancer was an experience that impacts all facets of grandparents' lives.

Sub-Theme: Steroids—Witnessing Changes to the Grandchildren. This theme explores grandparents' perceptions of the negative impact of steroid treatment on their grandchildren. Grandparents highlighted that the steroids changed their grandchildren, as seen in one GM's reflection that "the worst, worst part of it was watching [GDWC] disappear, her personality. She was gone." Grandparents found it challenging to see their grandchildren change so much and the discomfort caused but this aspect of treatment was hard to witness:

> I hated seeing it . . . my little special boy being so upset . . . so hungry . . . so angry and there was nothing I could do to help him . . . I felt so helpless. And then I had to watch [AC] to cope with it all (GM).

Steroids were seen as a necessary part of treatment, but they still lamented their impact, saying that "I know he had to have the drugs . . . but gosh they came as such a high cost . . . the impact . . . on my grandchild and [AC] was just horrible" (GF). Grandparents appear to have witnessed the full impact of steroids, and the side effects of these treatments were difficult for them to process knowing it hurt both the GDWC and their AC.

Family: Worrying About Everyone. This theme explores how grandparents worry about all their family members.

Sub-Theme: Double Whammy. This theme captures grandparents' feelings that having a GDWC meant that there were two levels of worry for both their AC and their grandchildren. Grandparents expressed what several grandparents termed the "double whammy." Explaining how difficult it was having to worry about two loved ones, one grandparent said, "It's a double blow . . . I think as grandparents it's very hard because you got your children, you are concerned about . . . how they are coping, and then the grandchildren as well" (GF). Witnessing their AC having to care for a child with cancer and not being able to prevent the distress was difficult, as one grandparent recalled, "The hardest bit for me dealing with it . . . is that [AC] is my baby, and I can't protect my baby . . . it's how she feels because she can't protect her baby, but she's my baby" (GM). Grandparents appeared to have felt a sense of helplessness that they couldn't protect their AC from the trauma. Several grandparents expressed concern about the long-term impact on their AC, as seen in this quote:

> This has to have an impact and I worry about [my adult daughter's] health . . . it takes such a toll on her . . . she doesn't eat properly and hardly sleeps . . . I try to help as much as I can, but he [GDWC] is so very, very sick, she never takes time to look after herself . . . so I have to worry about them both being sick . . . but only one is being taken care of . . . what is the long-term impact? (GM)

The complexity of the emotions that grandparents experience is evident, showing they worry for both the long-term health of their grandchildren and their AC.

Sub-Theme: Siblings—Adjusting to New Roles. This theme outlines grandparents' thoughts regarding the impact on siblings of having a brother/sister diagnosed with cancer and their changed relationship with grandchildren. Many grandparents highlighted that they worried about the effect on siblings, with one stating, "It's so hard on [the sibling], she misses her mum and her brother and worries so much . . . It's horrendous . . . and then she [sibling] is often upset with me for taking her away from her mum" (GM). Several grandparents in our study moved into their AC's home or had the sibling(s) of the GDWC move in with them to provide care. Other grandparents provided care for long periods when the child's parents were at the hospital. These grandparents described how the change in roles (from grandparent to having to provide parental responsibilities) was difficult and they missed the pure grandparent role:

> Look, the hardest bit for me as a nana is taking on that parent role . . . I've always been close to these kids. . . . Once [sibling] said to me, "Oh, nana never says no." Suddenly I had to say no. . . I'm doing the parenting role . . . so, when she needs to have rules, I have to say no. (GM)

Several grandparents also noted that it was difficult for siblings to have both grandparents and parents taking care of siblings as they often had different discipline styles. One grandparent who had moved in with their AC and grandchildren stated, "It's really difficult for children, dealing with dad telling them one thing and grandparents telling them another thing" (GM). In these quotes, we can see that the grandparents were aware that they had different ways of caring for the siblings and that having two different routines created stress for the siblings.

Sandwich Generation. This theme details the experiences of grandparents who found themselves caring for multiple generations: their grandchildren with cancer, their AC, and their elderly parents. Some grandparents discussed the challenges of worrying and caring for their AC and grandchildren but also having to care for their elderly parents:

> I'm the one that's always strong for everyone. I'm supporting the family. I'm the one that takes care of my mum and my dad and every appointment, doctors, this and that, powers of attorney . . . I seem to be the one that is helping everyone . . . That seems to be my role in the family. (GM)

These roles of having to care for different generations left some grandparents exhausted both emotionally and physically, with one GM reflecting:

> . . . there is no time for me to do anything but look after everyone else . . . some days I feel I'm going to collapse . . . but I can't do that everyone needs me . . . I should go to the doctor to deal with my [medical condition] . . . but I just don't have time. (GM)

Several grandparents also talked about the challenges of elderly parents with neurocognitive disorders who no longer could process the grandchild's diagnosis. One GM described how "[my] mother understands, but she doesn't remember. We talk today and she [participants' mother] . . . gets upset because she'd never heard." This grandparent also discussed the need to "protect my parents [great grandparents]" from the stress of the cancer diagnosis. The challenge of worrying about the impact of childhood cancer on the different generations and "protecting everyone" left grandparents feeling, as one GF described it, as though they were "carrying such a large burden . . . it's so many roles."

Balancing Work. This theme details the experiences of the 15 grandparents who were still working while their grandchild had cancer. Many expressed that it was difficult to combine working while worrying about their grandchild. Work was difficult on both an emotional and practical level. Emotionally, the juxtaposition of witnessing childhood cancer treatment and the normal routines of work was difficult. As one GM recalled:

> Emotionally, I found it quite difficult to leave there [the hospital], go to the office, and sit at my desk and think, how can I get back into work . . .. Some nights when I'd been . . . at the hospital [overnight] and had to go to work [in the morning] it just felt weird, and I thought, I'm not sure I can do both. (GM)

On a practical level, the demands of being in the hospital assisting with care and then going to work were exhausting for grandparents. One grandmother stated, "I was working and then going to the hospital till late at night and then repeat . . . I was exhausted but I had no choice . . . I had to do both . . . but at my age it was hard." Grandparents also reported that it was often challenging to deal with routine aspects of work life:

> I found it really hard to go back to work. It took me four weeks to stop being tearful . . . I just didn't engage in small talk. I found talking about mundane things like, "I have to buy [an] outfit" . . . I just couldn't participate in that small talk. (GM)

The grandchild's cancer diagnosis impacted the grandparents' work life, with some grandparents indicating that they took time off from work to help care for their GDWC. This included taking "three months off . . . [because] I can't do this and work as well" (GM). Others reported reducing work "I take my long service leave one day a week so I can be there [at the hospital]" (GM). They also adjusted work hours to enable availability to support their AC and grandchildren, with one GF explaining, "I just spoke to my boss about less hours and told him family come first . . . that meant less money, but you know . . . it's what you do." Many grandparents had the stress of juggling conflicting work and family responsibilities.

It's Like Suddenly a Door Opened. This theme covers grandparents' emotions regarding knowing children who had died from cancer. Grandparents who spent extended time on the ward were exposed to the loss of other children, and this had a profound impact on grandparents, with one explaining, "I've known so many children that have died now. It's hideous that I have known children so well and they are dead, and I've been to children's funerals" (GM). Grandparents reflected that they felt unprepared, stating that, "I see updates [Facebook] when another kid goes from the ward [dies] . . . It's like suddenly a door opened and I know of this world that always existed, but we are not aware of it unless you really know somebody" (GM). Many indicated that they saw social media pages of children that they met on the ward and that reading about children they knew who were dying was hard: "I saw the [Facebook] update on [child in palliative care] . . . I just can't see that without crying . . . I cry when I read [mother of a deceased child]'s posts" (GM). Some grandparents reflected that their friends did not understand, stating, "I think they're taboo in western culture, or not just western [culture], in a lot of cultures. You don't talk about certain things like that [death]" (GF). Grandparents appear to have felt isolated due to the lack of understanding by friends and the social taboos regarding death and children's deaths specifically. Some grandparents experienced multiple deaths:

> The little girl [with cancer] that [GDWC] shared a room with, passed away and that was devastating . . . your heart breaks, no child should die . . . then after the first [death] you put up a bit of a barrier . . . and you move on to the next one and the next one and the next one and all the time hoping that it wasn't going to be your grandchild. (GM)

We can see in this quote that the death of children from cancer impacts grandparents on two levels: first, from the sadness of seeing a child die, and second, because it increased their fear about the possible outcome for their grandchildren.

Discussion

In this study, we have explored the lived experience and multiple ramifications of having a grandchild diagnosed with cancer. We highlighted the emotional distress that grandparents encounter when their grandchildren are diagnosed and treated for cancer and how it impacts their lives. Ecological systems theory explains that individual family members do not exist in isolation and that each person's experiences affect those around them (Bronfenbrenner, 1979). In our study, we can see that the diagnosis of the grandchild's cancer impacts grandparents, and they experience many similar reactions to parents, including distress at witnessing their GDWC's treatment. The ecological systems theory also posits that individuals sit within a larger socio-cultural macrosystem that influences their experiences. In our study, we can see that changes in demographics and cultural attitudes to workforce participation at the macro level have increased the negative impacts of a grandchild's diagnosis, with grandparents now having to care for multiple generations and combine work with supporting their families (Bronfenbrenner, 1979; Buchanan & Rotkirch, 2018).

Many of the existing studies exploring grandparents' experiences have not included data on grandparents' work status or discussed the experiences of work (Kelada et al., 2019; Wakefield et al., 2014b). More than 75% of grandparents in our study were working either part-time or full-time. In recent decades, due to the aging population and the subsequent pressure on pension systems, the mandatory retirement age has increased labor force participation among older workers (Nagarajan & Sixsmith, 2023; Pilipiec et al., 2021). This coupled with cultural changes which have seen the increasing participation of women in the workforce has meant that more grandparents will still be in the workforce when their grandchildren are diagnosed with cancer (Moussa, 2019a). The balancing act for grandparents of combining both work and assisting in caring for their family was an issue raised frequently by grandparents and one of the major challenges.

Grandparents described both practical and emotional challenges. Practically, grandparents described the challenges of working during the day and then spending time caring for either siblings or GDWC. Emotionally, those grandparents who worked explained that it was difficult to deal with the mundane aspects of work when dealing with the trauma of childhood cancer. Previous research observed that grandparents often find it difficult to talk to friends and that this creates tension in friendships (Moules et al., 2012a). Our study expands this aspect to show that, for those in the workforce, normal office communication between colleagues is challenging. In addition, many grandparents altered work hours to accommodate their grandchild's treatment. Research has shown that parents of sick children must modify work patterns and that families can face a loss of income due to changed work hours (Kelada et al., 2020). In our study, we can see that the financial impact of childhood cancer is not isolated to the immediate nuclear family and affects grandparents.

An important and novel finding of our study is the role that grandparents play in caring for three generations. Changing demographics and an aging population exacerbate the stress grandparents of children with cancer experience, as they are now often required to juggle caregiving for their elderly parents/relatives as well as assisting in caring for GDWC and supporting their AC (Moussa, 2019). Our participants highlighted the emotional toll that these differing roles caused and the difficulties in trying to care for multiple generations. They also observed that these conflicting demands meant that there was often no opportunity to engage in self-care. Previous research has shown that grandparents rarely seek support for their own needs, and it can be theorized that the need to care for multiple generations will only exacerbate this lack of self-care (Wakefield et al., 2014a).

Grandparents in our study outlined the overwhelming impact of their grandchild's cancer diagnosis and treatment. This aligns with previous reports that grandparents described childhood cancer as one of the worst experiences when compared with other life events (Charlebois & Bouchard, 2007; Moules et al., 2012a). Despite not being the primary carer of their GDWC, grandparents experienced many emotions that were like those experienced by parents, including feeling devastated and having trouble accepting the diagnosis (Davies et al., 2023; Kahriman et al., 2020; West et al., 2015). The grandparents in our study played an important role in helping to provide care for the GDWC, including assisting with care on the ward. In this study, we have expanded on current knowledge to thoroughly explore the impact of assisting in providing care for GDWC.

Childhood cancer results in a crisis in the family, and parents often rely on grandparents to step in to provide support in multiple ways (Findler, 2014; Kelada et al., 2019). In our study, grandparents described providing practical support for the whole family, particularly in caring for siblings (Flury et al., 2021). Aligning with previous research, grandparents described feeling concerned about the impact on siblings and were worried about the disruption to their "normal" childhood (Flury et al., 2021; Wakefield et al., 2014a).

Our study adds to our understanding regarding siblings and demonstrates the negative impact on those grandparents who provided live-in or frequent care for siblings. All family members sit within social systems and have set roles within the family, and when a child is diagnosed with cancer, these roles and responsibilities often change (Tan et al., 2010). In modern society, grandparents normally spend time with grandchildren without the normal "strict routines" of everyday life. This normal role of grandparents has been described as "pleasure without responsibility" (Backhouse & Graham, 2011). In our study, the need for grandparents to move in or take over the parental roles for siblings appeared to have a negative impact on their role as grandparents, with grandchildren often seeing them in the "strict" parental role. The change in roles and shift to "parental role" appears to have created tension, and grandparents appeared cognizant that the shifting roles within the family created stress for siblings. They also highlighted that they missed the grandparenting role.

The grandchild's cancer diagnosis significantly impacted the grandparents' lives at multiple levels of the ecological system, including their social functioning. There has been conflicting research on the impact of childhood cancer on grandparents, with Findler (2014) finding that grandparents were able to maintain normal social support activities. In contrast, Hall (2004) showed that grandparents put their lives on hold to support grandchildren, including limiting social activities. An important insight that our study has revealed is that many grandparents modify their social functioning in response to their GDWC's compromised immune system. Grandparents observed that their lives changed not only due to time commitments of supporting their AC and grandchildren but also due to concerns about spreading infections to their grandchildren. It appears that grandparents experience many similar responses to parents as seen in their reactions to the need for infection control (Davies et al., 2022; Young et al., 2002). Research about parents has shown that fear of infections was a cause of anxiety, and in our study, we can see that grandparents shared similar feelings regarding limiting their social life to protect their grandchildren (Yildirim Sari et al., 2013). Immune suppression experienced by children with cancer affects not only the nuclear family of parents and children but also those who are proximal to the family.

Consistent with previous studies, a major finding of our study was that grandparents experienced worry on two levels, both for their grandchild and for their AC the so-called "double grief" phenomenon (Charlebois & Bouchard, 2007; Flury et al., 2021; Hall, 2004; Wakefield, 2014a). Grandparents worried about the child with cancer and the sense they could not protect their AC from the pain of witnessing the cancer treatment. Previous researchers have found that parents, particularly mothers, experience distress after their child's cancer treatment and worry about the long-term impacts on their children (Davies & O'Connor, 2023). Our study adds to our understanding of grandparents' experiences of childhood cancer, showing that grandparents are cognizant of the potential for negative long-term psychological and physical impacts, not only on their grandchildren but also on their AC. Again, we demonstrate that grandparents' worry occurs at multiple levels, with concern not limited to their GDWC.

Many grandparents described feeling that having a GDWC who could die was against the natural order of things. Bury's theory of "biographical disruption" can be used to understand this reaction (Bury, 1982). This theory proposes that people have a predetermined vision for how their lives should be and that illness can "disrupt this vision." Grandparents described how it should not be their grandchildren facing death, and that the "natural order of things" is that they should die before their grandchildren. This aligns with existing research that reported that grandparents felt a "sense of injustice" that their grandchildren were suffering (Charlebois & Bouchard, 2007).

In our study, grandparents were often involved in caring for grandchildren and were thus exposed to many of the realities of childhood cancer, including the death of children (Flury et al., 2021). We can see in our sample that individuals do not exist in isolation, and the larger social values in the macro system toward death and grief influence how grandparents experience childhood cancer (Bronfenbrenner, 1979). Current societal taboos around discussing death, particularly that of children, exacerbated the negative effects of child mortality from cancer. For some grandparents in our study, witnessing the death of children increased their fears regarding the outcomes for their grandchildren. Consistent with previous research, grandparents fear the long-term recurrence of their grandchild's cancer, and seeing children die whom they had often become close to while attending the ward exacerbated this fear (Charlebois & Bouchard, 2007). Grandparents commented that they followed the Facebook pages of other children on the ward, and it could be suggested that the increase in exposure due to social media may have increased the level of distress when children die.

Limitations

A potential limitation of our study is that there may have been a selection bias, as only those grandparents who were involved in their grandchild's care may have volunteered to participate. This may mean that it does not reflect the experiences of those who are less involved in a GDWC's care. To address this concern, we used snowball sampling, requesting that participants passed on study information to other grandparents, including grandparents who visited the ward but did not provide respite care for their grandchildren. There were also no participants from culturally and linguistically diverse backgrounds. This lack of diversity may mean that the study findings are less transferable. Attempts were made to address this and two participants from non-English-speaking backgrounds expressed interest, but they withdrew before the interview, explaining that they felt nervous about the interview. This may be reflective of their language skills, and further studies are warranted to explore the needs of grandparents from non-English speaking backgrounds.

Clinical Implications

There are currently limited supports available to grandparents of children with illness/disabilities, with many health care services considering them external to the nuclear family (Novak-Pavlic et al., 2021). Grandparents play a vital role in the family of children with cancer, and they experience many of the same stressors as parents, including balancing work and care of the children—both that of siblings and the child with cancer. Importantly, we have shown that some grandparents now must manage juggling caring for multiple generations. It is therefore vital to provide psychological support to grandparents that recognizes the distinct impact of childhood cancer, particularly the impact of stress from worrying about multiple generations. Grandparents find it difficult to witness their grandchildren receiving treatment and need to be provided with appropriate psychosocial support to adjust to the realities and complexities of childhood cancer treatment. This should include providing information and advice on the impacts of specific aspects of treatment such as steroid treatment. The findings of our study would be beneficial to HCP in allowing them to understand the multiple demands on grandparents. Family members are interdependent and supporting grandparents helps the whole family. Care provided to families of children with cancer needs to be family-focused and include a consideration of the impact on grandparents.

Conclusion

In our study, we demonstrate that childhood cancer has a ripple effect, and its impacts are not limited to the nuclear family. Here, we have provided a thorough exploration of the impact of a grandchild's cancer diagnosis, increasing our understanding of the ways in which grandparents' lives are changed at multiple levels of the ecological model, including work, friends, social life, and roles within the family. Importantly, we have expanded upon existing knowledge to show that with an aging population, some grandparents now must juggle competing demands in both working and caring for aging families while trying to support their AC and grandchildren. Grandparents find themselves "sandwiched" between having to care not only for their AC and their grandchildren with cancer but also for their elderly parents. This burden created anxiety for grandparents as they feel squeezed between competing demands. These findings reflect changing demographics within society and the need to be aware of these issues when providing support to families and grandparents of children with cancer. We have highlighted the need for care provided to families of children with cancer to be aware of the role grandparents play and the need for support to include an acknowledgment of their role in the family.

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Supplemental Material

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Moira O'Connor, PhD, is an associate professor and a senior research fellow in psychological and psychosocial aspects of cancer and palliative care at Curtin University in the School of Population Health. She works with patients, families and carers, and health professionals. Moira has a keen interest in children, adolescents, and young adults (AYA) affected by cancer (parental cancer, siblings of children diagnosed with pediatric cancer and children and AYA diagnosed with cancer). Recent publications include "It's Always Been a Second-Class Cancer": An Exploration of the Experiences and Journeys of Bereaved Family Carers of People with Sarcoma" in *Cancers* (2021, with G. Smith et al.), "A Systematic Review of Interventions to Reduce Psychological Distress in Pediatric Patients Receiving Radiation Therapy" in *Patient Education and Counseling* (2019, with G. Halkett), and "'Torn in Two': Experiences of Mothers Who Are Pregnant When Their Child Is Diagnosed with Cancer" in *Qualitative Health Research* (2022, with J. Davies).

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Clinical recommendations

This research highlighted several areas where improvements can be made to support grandparents when their grandchild is diagnosed with cancer including:

- Delivery of psychological support services specifically tailored to grandparents' individual needs including the implementation of peer support programs to enable grandparents to support each other.
- Increased delivery of information to grandparents regarding childhood cancer by HCPs within the hospital setting, including explanations of treatment processes to reduce anxiety.
- Increase in support for those grandparents who provide care on the ward, including acknowledgment of the difficulties of juggling caring for multiple generations.
- Provision of grief counselling services when appropriate to grandparents who experience loss from witnessing other families' children die from cancer.
- Support within the community for grandparents who provide care for siblings including flexible working arrangements to enable grandparents to combine work and caring for their families.

CHAPTER 7 - Study 5: “I don’t get to play with my mum anymore”: Experiences of siblings aged 8-12 of children with cancer: A qualitative study.

Chapter overview

This chapter consists of an article examining the experiences of siblings aged 8-12 of children diagnosed with cancer. The decision was made to focus on a younger age group after initial interviews showed that younger participants expressed distinct reactions to their sibling’s diagnosis. An overview of existing literature identified that research had often focused on older or broader age groups, and there was little which specifically examined younger siblings’ experiences. This article then aimed to fill this gap in knowledge. It explores the specific issues that younger siblings face when their brother/sister is diagnosed with cancer. This article has been submitted to the *Journal of Pediatric Hematology/Oncology Nursing* and has been accepted awaiting publication.

What this adds to the literature.

Other studies of siblings of a child with cancer have focused on a broad range of ages, including young children, adolescents, and young adults. This limits the detailed exploration of younger children’s experiences. Given the unique developmental considerations inherent to young children, as well as the relative paucity of data specifically exploring younger siblings’ experiences, our study fills this gap by exploring the experiences of siblings aged 8–12 years following a brother or sister’s cancer diagnosis.

These findings provide important understandings of the ways in which younger siblings' developmental and cognitive skills impact their experiences of childhood cancer. Furthermore, it highlights that missing playing with siblings and families has a significant impact on them. It also suggests that their age and cognitive skills impact their abilities to understand the cancer diagnosis. These findings will enable appropriate supports to be provided to siblings that match their cognitive and emotional maturity.

"I don't get to play with my mum anymore": Experiences of siblings aged 8-12 of children with cancer: A qualitative study.

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Conflict of Interest

The authors have no relevant financial or non-financial interests to disclose. Authors declare no conflict of Interest.

Abstract

Background: Siblings of children with cancer have been shown to experience disruption in multiple domains including family, school, and friendships. Existing literature on siblings' experiences focuses on older children or on a broad range of ages.

Aim: To explore the experience of siblings aged 8-12 years when their brother or sister is diagnosed with cancer.

Method: A qualitative design incorporating phenomenology as the theoretical framework was used. Participants were recruited from across Australia via notices on social media sites and by the distribution of flyers. We used thematic analysis to analyse the data. Data was collected via semi-structured interviews conducted either in person or online.

Findings: A total of 13 siblings (seven boys and six girls) aged between 8-12 years (M = 9.8, SD = 1.6) were interviewed. Seven main themes were identified. These were "It was really hard": Reactions to the cancer diagnosis; "I'm really angry": Emotional and Physical Responses to siblings' treatment; "I pretend teddy is real": Play as an outlet; "It was very lonely": Missing their siblings; "I missed out on a lot of fun": Disruption of activities': School, sports, playdates, and parties; Change and Transition and "Making a difficult situation worse": COVID-19 Pandemic.

Discussion: Findings extend the current understanding showing that younger siblings developmental and cognitive skills impact their experiences of childhood cancer. Younger siblings outlined the many losses they experienced which demonstrated a need for a comprehensive and tailored program to support young siblings aged under 12 of children with cancer.

Every year in Australia ~ 800 children aged 0-14 will be diagnosed with cancer (AIHW, 2022). While survival rates have improved, it remains a life-threatening illness that causes significant disruption to the entire family (Kahriman et al., 2020). Treatments are often long, involving frequent hospital admissions, chemotherapy, radiotherapy, medications, scans, outpatient appointments and care in the home (Castellano-Tejedor et al., 2017). This article focuses on the impact on siblings of children with cancer, which have been shown to experience disruption in multiple domains of their lives, including family, school, and friendships (Guggemos et al., 2015; Long et al., 2015; Salmon & Bryant, 2002; Weiner & Woodley, 2018).

Background

Siblings of children with cancer can experience significant negative emotional ramifications, including anxiety, depression, reduced quality of life (QOL) and clinical levels of post-traumatic stress symptoms (PTSS) (Alderfer & Hodges, 2010; Houtzager et al., 2003; Kaplan et al., 2013). Siblings report feeling fearful and experiencing distress at having to witness their brother or sister undergoing painful treatment (Porteous et al., 2019; Prchal & Landolt, 2012; Weiner & Woodley, 2018). Moreover, qualitative research highlights that siblings carry significant worry about the child with cancer dying (Weiner & Woodley, 2018; Woodgate & Degner, 2003). To alleviate some of these fears, siblings have highlighted that they would like more information about their brother’s/sister's cancer diagnosis and treatment (Long et al., 2015; Tasker & Stonebridge, 2016; Van Schoors et al., 2019)

Stress and anxiety lead to various negative consequences which included increased rates of absenteeism and deterioration in school grades (Alderfer & Hodges, 2010; Long et al., 2018; Weiner & Woodley, 2018). Increased rates of absenteeism may exacerbate psychological distress for siblings as school has also been shown to provide some benefit in providing distraction from the stress of cancer (Prchal & Landolt, 2012; Salmon & Bryant, 2002). It has also been demonstrated that school provides an opportunity for siblings to access emotional support from friends and teachers (Porteous et al., 2019; Prchal & Landolt, 2012).

The family unit comes under significant stress when a child is diagnosed with cancer. Siblings are often cared for by relatives (most frequently grandparents) or friends, while one parent typically gives up or reduces hours at work to care for the child with cancer (Deavin et al., 2018; Long et al., 2018; Van Schoors et al., 2019). Siblings, therefore, experience both emotional and physical separation from their parents and report missing a sense of family cohesion (Long et al., 2018). Given the stress caused by a childhood cancer diagnosis, the cancer treatment becomes the family's primary focus. In previous research, siblings have expressed that they feel overlooked and jealous of the attention the child with cancer receives (O'Shea et al., 2012; Porteous et al., 2019; Van Schoors et al., 2019; Weiner & Woodley, 2018), which includes feeling envious of the gifts that the brother/sister with cancer receives (Prchal & Landolt, 2012; Tasker & Stonebridge, 2016). Studies have shown that siblings understand why their brother/sister receives additional gifts but report feeling sad that they never receive any special treats/gifts (Van Schoors et al., 2019).

The complexity of siblings' emotions is evident insofar as, despite siblings feeling that they need more support, they also frequently report that they want to protect their parents and family from worrying about their needs (Deavin et al., 2018; Porteous et al., 2019; Weiner & Woodley, 2018). Some siblings also report growing closer as a family during treatment as they work together to support the child with cancer (Prchal & Landolt, 2012). Research has also highlighted positives such as growth in maturity, compassion, empathy and autonomy, with siblings highlighting the need to be ‘grown up’ to support their family (D'Urso et al., 2017; Pariseau et al., 2020; Van Schoors et al., 2019).

Study rationale

A developmental lens is crucial to understand young siblings’ responses to childhood cancer, as these responses are mediated by shifting language, cognitive, and emotional regulation (ER) skills (Best & Miller, 2010; Salmon & Bryant, 2002). ER is the ability to manage and respond to emotional experiences, and this changes throughout childhood (Bariola et al., 2011; Best & Miller, 2010). Older children have more sophisticated ER strategies such as cognitive reappraisal and are better able to self-regulate emotions, whereas young children typically resort to direct emotional expressions such as angry outbursts (Bariola et al., 2011; Salmon & Bryant, 2002). According to Piaget’s theory of cognitive development, children go through different stages of understanding as they age, which impacts their ability to process information (Ahmad et al., 2016). During the concrete operational stage during pre-adolescence, children (7–11 years) have not yet developed the skills necessary to think in hypothetical terms and they process information differently to adolescents in the formal operational stage (Ahmad et al., 2016; Beilin, 1992, 1992). Executive functioning skills also change throughout childhood, with adolescents possessing more sophisticated skills (Bariola et al., 2011; Best & Miller, 2010).

Most of the existing literature focuses on older children (above 12 years) and young adults, and experiences are often described retrospectively (Long et al., 2018; Porteous et al., 2019; Prchal & Landolt 2012; Van Schoors et al., 2019; Weiner & Woodley, 2018). This may be due to the perception that older children are better able to articulate and recall their experiences

(Prchal & Landolt, 2012). Other studies have focused on a broad range of ages including young children, adolescents, and young adults (Kobayashi et al., 2015; Pariseau et al., 2020). However, these studies often have heterogeneous samples, which limits the detailed exploration of young children's experiences. Long et al. (2015) and Weiner and Woodley (2018) argue that developing a detailed understanding of younger siblings' experiences can facilitate the provision of developmentally appropriate support. Given the unique developmental considerations inherent to young children, as well as the relative paucity of data specifically exploring their experiences, our study sought fill this gap by exploring the experiences of siblings aged 8–12 years following a brother's or sister's cancer diagnosis.

Methodology

This research was informed by a phenomenological approach, which can be used to explore how people make meaning from their experiences (van Manen, 2017; Wojnar & Swanson, 2007). We used a qualitative design involving interviews with siblings of children with cancer. Our study was part of a larger study that used Bronfenbrenner's ecological model as a lens to explore individual family members' experiences of childhood cancer. The ecological model posits that children do not sit in isolation and are influenced and shaped by the social context within which they are embedded (Härkönen, 2007). Ethical approval was provided by Curtin Ethics Committee (ID number). Data were collected between January and July 2022.

Inclusion and exclusion criteria

This project recruited siblings aged 8–15 years; however, for the purposes of this study, we focused on children aged between 8 and 12 whose sibling had been diagnosed with cancer and was currently undergoing treatment or had completed treatment in the previous 15 months. Half-siblings and stepsiblings were eligible for inclusion in this study. Siblings of children who were deceased were not eligible.

Recruitment

Participants were recruited using convenience sampling and snowball sampling where parents of participants passed on information to other families. Recruitment flyers were posted on oncology Facebook pages on children's hospital sites across Australia. Flyers were also posted on social media by organisations that support families of children with cancer. These flyers requested that parents consider if their children (siblings of children with cancer) would be interested in participating in the study. They were asked to contact (JD) by email or phone for more information. (JD) then sent a flyer for the children and a participant information sheet in two forms (i.e., in adult language and child-friendly language). Once children had indicated interest, (JD) emailed the parents a demographic form and consent form (with assent for children). Consent forms were provided in two formats, one with a simple language flip chart format for children 8–9 years old, which included emojis/pictures (the flip chart is available from the corresponding author) and a plain language written format. Once consent had been obtained, (JD) then organised the interview with parents.

Data collection

We collected data via semi-structured interviews with siblings. An interview guide (available from the corresponding author) was used, which contained nine open-ended questions. Our interview guide was reviewed by two consumer representatives who were parents of children who had been diagnosed with cancer. An example of a question was "Could you describe how you felt when you were told your brother/sister had cancer?" Before sibling interviews, brief semi-structured telephone interviews (average 12 minutes) were conducted by (JD) with a parent/carer to gather information on the cancer diagnosis and information regarding the sibling's experiences—for example, if they had lived with grandparents during their treatment. We completed sibling interviews (JD) via Zoom/Teams or in person. Audio recordings of the interviews were made with a digital recorder. Interviews were completed without parents in the room as we considered that siblings might be reluctant to voice their thoughts in front of their parents/carers (Deavin et al., 2018). To ensure that siblings were giving informed assent, (JD) verbally explained the aim of our study in child-friendly language. (JD) also explained that they could stop at any time and that their parents would not be informed of their answers (unless it was for the child's safety).

We began all interviews with (JD) asking questions regarding hobbies/sports to develop rapport with the children. Before the interviews, parents were asked if their children would like colouring sheets to complete during the interview and these were provided by email or in print. This provided an activity to maintain the children's engagement. At the end of the interview, all participants were thanked given a $20 gift card. (JD) provided support service information to parents following the interview. (JD) advised parents to enquire with their children after the interview to determine whether talking about their brother's/sister's cancer caused distress and to contact support services if necessary.

Data analysis

We completed verbatim transcription of the interviews as soon as possible after each interview online via computer rev.com software, or manually by (JD). Thematic analysis was then completed based on the steps described by Braun and Clarke (2021). The first phase involved (JD) listening to all transcripts to develop familiarisation. The transcripts were then read and re-read by (JD) to look for common patterns. After reading the transcripts, codes were developed and noted in the margins using a paper-based system. These codes were reviewed and analysed by all authors to develop themes across the data. Themes were then reviewed and refined before names were given. Themes were then converted into a final report by (JD) to outline the findings.

Rigour and reflexivity

Thematic analysis is a flexible and fluid process acknowledging the role of the researcher in analysis. As Braun and Clarke (2021) contend, qualitative research is about stories and requires a reflexive approach, where the researcher is aware of their responses and how this might influence data analysis. (JD) is PhD student with extensive qualitative experience within the oncology setting and an insider researcher having had a child diagnosed with cancer. (JD) kept a reflective journal throughout the research process to record responses to the data and explore how experiences may have influenced the research (Berger, 2015; Johnson et al., 2020). This was then discussed with the research team. We also ensured rigour by using the COREQ checklist (Tong et al., 2007). An audit trail was kept throughout the research process to record all decision-making processes (Braun & Clarke, 2021). Initial findings were discussed with consumer representatives for feedback, with consumer representatives reflecting that from their perceptions they appeared to be an accurate analysis of siblings' experiences.

Research findings

Initially, 15 families volunteered to participate, but one family did not proceed due to time constraints and one family withdrew after the child changed their mind about participating. The final study comprised 13 siblings (seven boys and six girls). The participants' ages ranged from 8–12 years at time of interview (*M* = 9.8, *SD* = 1.6). Two siblings were half-siblings. Interviews ranged in length from 15 to 51 minutes (*M* = 25, *SD* = 12). Additional demographic details are provided in Table 1.

Table 1

Participant Socio-demographics (N =13 participants)

	N	%
Gender		
Male	7	54
Female	6	46
Treatment status		
Out of treatment	2	15
In treatment	11	85
Sibling		
Older than child with cancer	7	54
Younger than child with cancer	6	46
Child's primary diagnosis		
Brain cancer	2	15
Sarcoma	2	15
Haematological	7	54
Other	2	15
Stayed with relatives/friends		
Yes	8	61
No	5	38

Two children's' treatment for cancer had included stem cell transplant (requiring extensive isolation) and one child with cancer was being treated for relapse. All but one interview was completed online. Eight children used toys, photos, or pets during the interview to aid in discussing their experiences. Seven themes were identified below.

"I just felt mad": Reactions to the cancer diagnosis.

This theme explores siblings' emotional responses to being told about their brother's/sister's cancer diagnosis. A common description was that they felt angry. For example, one brother described that "I was upset… lots of feelings… I was so angry" [9-year-old]. This was often followed by an explanation that they did not understand why they had the emotions. One described that "It was really hard…it made me mad, I don't know why. I just felt mad" [8-year-old]. Responses varied based on their experiences of cancer within their family. For some participants, previous experiences of family members dying from cancer created fear that their sibling would die "because my papa and my grandmom had cancer and they both passed away… so that made me scared [8-year-old]". Another recalled their thoughts when informed about their sibling's diagnosis:

> I know another family member who had cancer and they… passed away... At first, it was very scary because seeing how sick [my sister] was and knowing that such a high rate of people with cancer that have passed away…Then, after July, once my other family member passed away, it just brought all those feelings that [my sister] is not going to make it. [9-year-old]

Some siblings also discussed having heard about cancer in movies or on social media and they thought it meant children died, "you know, like that program on Netflix where they go on holiday when she is sick and then dies... so I thought that is what happens when kids get cancer… they die" [9-year-old]. For siblings who had little knowledge or personal experience of cancer, the response to being told of the diagnosis was often more muted. One sibling described that "I didn't actually realise it was that bad… It was annoying and quite hard to explain but it was annoying" [9-year-old].

"I'm really angry": Emotional and physical responses to sibling's treatment.

This theme explores siblings' emotional and physical responses during their brother's/sister's cancer treatment. Several described having trouble sleeping and having bad dreams: "I always had this one nightmare… that I was in the hospital with [my brother] … then doctors would come running…that he's not breathing…and then he died in the end… I'd wake up screaming" [8-year-old]. When asked if they told their parents about the bad dreams, most reflected that they sometimes told their extended family, but they were extremely reluctant to tell their parents because "I didn't want them to be worried because, like, they already have to deal with all of [my sister's] medical stuff" [11-year-old]. Thus, siblings often concealed their emotional responses to reduce the burden on parents. Anger appeared to be more common in males, with some boys explaining that despite the strong negative emotions, they very rarely spoke to anyone about it—for example, "I don't like telling people… yeah... not talking about that stuff… I'm a boy, you know, and stuff" [11-year-old]. In general, boys appeared to find it more challenging to express their emotions.

The feeling of anger that many siblings felt in response to being informed about the cancer often lasted beyond the initial stage, with several siblings whose brother/sister was in late-stage or off treatment reflecting on how it had changed them as people, noting that they were now angry people. For example, “Well, I’m really angry because of [my sister], and before that, I used to feel… happy” [8-year-old]. One brother described, “It's changed me a lot because I punched a hole in my door because I got angry”.

These emotions and feelings also impacted siblings physically, with several describing somatic symptoms including stomach aches—for example, “Yes, because I usually cry whenever someone talks about [my sister], and every night I always get a sore tummy just from crying about it” [8-year-old]. Four siblings talked about having headaches, with one attributing it to “worrying all the time” [9-year-old].

“I pretend teddy’s real”: Play as an outlet.

When asked how they dealt with the emotions regarding their sibling’s cancer diagnosis, responses tended to focus on not sharing their emotions with caregivers. The main strategy siblings used to manage the stress was imaginary play and confiding their emotions to inanimate objects. One sibling explained, "I pretend that my teddy's real, so I talk to him, or the toys... would you like to see him?” [8-year-old showing teddy to interviewer]. Another described, “I just talk to… toys and get a picture of [my sister] and talk to it” [8-year-old]. Others described talking to pets to express their emotions: “It's hard… when you're not around parents or something and you have any problems. I like to talk to my cat because I know she can't tell anyone. The other day we were doing trust circle at school, and I said pet and she was like, ‘What do you mean? How can you do it to a pet?’ I'm like, ‘Well, they can't tell anyone, so the secret is safe for them’” [8-year-old]. Several of the siblings talked about playing with the toys they used to play with their brother/sister: “When I’m missing him, I get out his toys… it makes me feel closer to him” [9-year-old].

“It was very lonely”: Missing their siblings.

Sub-theme: Missing their playmate. This theme explores siblings' feelings regarding missing the opportunity to play with their brother/sister with cancer. Siblings expressed that not being able to play with their siblings made them sad. The child's cancer treatment often meant the brother/sister was in the hospital for long periods—for example, "she was gone for so long… months at a time… we used to play dolls every day, but now I had no-one to play with… it was very lonely” [8-year-old]. One sibling explained feeling “lost without [my sister]”, and another described “the house just wasn’t the same without him… it was way too quiet… and there was no laughter”. Siblings appeared to have missed having a playmate and someone to spend time with. Siblings described how not having the sibling at home to play with made it hard to feel like they were a "normal family". Play and normal childhood activities appear to have shaped their vision of their family, and when this was impeded through the child's absence, siblings' views of their family were altered. As one described, "I liked to play soccer with all my siblings...Then it all stopped because it was different without having [my brother] there… so we weren't really doing family things anymore… it made me sad” [11-year-old].

Sub-theme: Missing how their brother or sister Used to Be. Another dimension of missing their brother/sister with cancer is related to the changes in the child’s personality and mood because of the treatment and medications. Many participants described how the personality of the child with cancer had changed dramatically. As they described, “[my sister] used to be a really sweet but now [she] is really bossy and grumpy" and "[my brother] used to be happy and nice but now is loud and angry". These personality changes impacted normal interactions with one participant, who described that she "missed playing with [my sister] like she used to be".

Many outlined that the children with cancer now "swore" and "said rude things" and that aggression, including biting and hitting, was common. It also impacted how the family functioned, with some explaining having to avoid the aggression: "Most of the time… I go up in my room… it makes me upset. Because he is always yelling". Several reflected that relationships and interaction had stopped: "[my brother] doesn't really talk to me anymore… I miss that lots". These comments demonstrate that the sibling bond and associated companionship were impacted by the behavioural changes that result from cancer treatment.

"I missed out on a lot of fun": Disruption of activities: School, sports, playdates, and parties.

Cancer treatment, and the resultant changes in family routine and fear of infection, meant that most siblings missed many aspects of 'normal' life. Siblings recalled that due to the risk of infection, they often had to miss school when there were "bugs going around". Several observed that this impacted their grades and "they missed important bits… so I didn't know what was going on when I went back…especially maths". One of the key aspects' siblings highlighted was not being able to attend sports/after-school activities due to fear of infection. Siblings appreciate the need but felt the loss: "It was hard. I get we had to not let [my brother] get sick, but I felt so lonely because all my mates kept going and I was at home… they did well in the [sports] finals and I wasn't there".

Another aspect that siblings discussed was missing out on social events, with one sibling stating, "I didn't really like going to parties… when [my sister] had cancer… it was too risky for [her]”. Another explained "I get invited to people's houses … I'd be like, ‘Sorry… I can't get my brother sick’ … I was glad that I was protecting [my brother], but it felt like I missed out on a lot of fun " [10-year-old]. Missing parties to protect their brother/sister caused one sibling to feel frustrated and angry:

> When [my brother] had cancer, my friend said that he couldn't invite me because [my brother] had cancer… as they didn’t want to risk him... It was at school, so I wanted to punch him, but… if it wasn't at school, I probably would have punched him. [11-year-old]

Several also noted that they missed out on birthdays celebrations. As one sibling explained:

> Mum was at the hospital. I didn't have none of my parents there. For our birthdays, we always get balloons. Helium balloons is what we like. It's not a big deal, but I didn't get balloons. Then I didn't have a birthday cake. I had just ice cream. It didn't really feel like my birthday. [9-year-old]

Another sibling described missing out on pocket money: “It's annoying, because I've been trying to save up for [specific toy for my birthday] for quite a while, so I used to get $5 to $1 every week for doing chores, and then once my nan started coming, I didn't really get any” [11-year-old]. We can thus see that their brother/sister's cancer treatment had impacts on many facets of sibling's social activities and celebrations.

“They don’t play with us anymore”: Change and transition.

Some siblings reflected that relationships with grandparents changed and that they didn't get to do 'fun stuff' with them anymore. As one brother observed, "[my grandparents] have got so strict now… they don't play with us anymore… like they used to, now it's just telling us what to do”. Siblings expressed appreciation for the care their grandparents provided but indicated that doing things differently in the home was frustrating. One brother reflected that "[my grandmother] did everything differently… and, like, put stuff away wrong… it was very annoying, and she is really grumpy now [9-year-old]". Another participant reflected that:

> Because I like my nana, but I was upset because [my brother’s] going to the hospital so much and it always felt like I didn’t know what was happening and nana was doing things so differently... not talking to me like she used to. [9-year-old]

Siblings also expressed that they missed being able to spend time with their parents in normal family time and their closeness to parents had changed. This was due to parents spending time at the hospital: "mummy isn't ever here… for a year I only saw her once or twice a month” [8-year-old]. Siblings reported that they spent little time with their parents, even when their parents were home. One sister observed “[my mum’s] always busy and whenever I want to play with her, she always says, ‘No, I'm busy with [your sister] …’ I don’t get to play with [my mum] anymore”.

Siblings also commented on the changes in parenting styles towards the child with cancer. For example, “[my brother] can full-on punch us and kick us and bite, which he does, and he doesn't get in trouble. He just gets a ‘don't do that’”. Siblings reported wanting additional parental attention: “I felt like [my brother] had a lot of attention, which I understand, but Mum still has three other kids…why aren’t we allowed to get away with stuff too?” One sibling observed that “mum and dad use to be so fair, now they aren’t…it’s changed, and it makes me feel so bad” [8-year-old].

“Making a difficult situation worse”: COVID-19 pandemic.

This theme explores the impact of the COVID-19 pandemic on siblings' experiences when their brother/sister was undergoing cancer treatment. The COVID-19 pandemic was highlighted as a factor that made a "difficult situation so much worse". This experience was multifaceted. COVID-19 hospital restrictions meant that siblings were unable to visit their brother/sister in the hospital:

> We'd been going in, but then soon as COVID hit, the hospital wouldn't let anyone in because of the risk of COVID in there, especially letting us up to the ward with all the kids with cancer who were at risk [9-year-old].

Siblings also described missing their brothers/sisters with cancer:

> I think that was one of the main challenges out of all of it that I faced because, being her big sister, was not being able to see her [due to COVID-19 restrictions] or hold her hand while she was there struggling... It really did hurt. [8-year-old]

Another aspect that siblings found difficult is that the COVID-19 pandemic meant that their ability to attend social events and school was reduced further. Several siblings described having to continue home-schooling when other kids were returning to school after COVID-19 lockdowns eased “Because I didn't get to school for about the rest of the school year… so I didn’t get to see anyone [and] it was so lonely when everyone went back but me” [9-year-old].

Several siblings described continuing infection control measures while outside the home to protect the sibling with cancer but that this meant they felt different to everyone else: “Here's a thing that worries me. I'm the only kid in my class who wears masks… Everyone just always bullies me about it, but I try to just ignore them. It's hard… I don't like it because it makes me feel weird, I don't know why” [9-year-old].

Discussion

The current study fills a gap in the research by exploring the lived experiences of young siblings with cancer to identify their specific needs. It also highlights the unique developmental considerations associated with their experiences. Siblings reported multiple ramifications, including a change in family relationships, missing play/family activities, changed routines, and sadness and anger in response to their brother/sisters’ cancer diagnosis and treatment. Our study also showed that young siblings use play and imagination to manage their emotions.

This study reveals that younger siblings often lack the cognitive skills to understand or process their emotions (D'Urso et al., 2017; Weiner & Woodley, 2018). Unlike previous research with older siblings (12–18 years), younger participants were not able to “vividly” describe their emotions and frequently seemed confused about their emotions (D'Urso et al., 2017). The ability to recognise and label emotions changes through childhood developmental stages and it is not until children are older that they can describe complex emotions (Pons et al., 2004; Salmon & Bryant, 2002).Young children in our study appeared to have a limited understanding of changes to their emotional and physical functioning, which appeared to leave them feeling angry and frustrated (Porteous et al., 2019). Evidence shows that the prefrontal cortex in young children is not fully mature, which can lead to poor ER skills (Bariola et al., 2011). Siblings in our study described difficulties in regulating emotions and in managing their responses to diagnosis and cancer treatment. Parents play an important role in the development of ER, and the absence of parents due to the cancer treatment may also be a factor in a sibling's difficulty in processing their emotions regarding their brother's/sister's cancer diagnosis (Gross, 2004). One significant difference found in this study compared with the previous studies is that young siblings did not express guilt regarding feeling jealous of the attention their brother/sister received (Tasker & Stonebridge, 2016).

Play is an important part of the cognitive, emotional, social, and physical development of children and has been recognised by the United Nations High Commission for Human Rights as a fundamental right of every child (Ginsburg et al., 2007; Yogman et al., 2018). Participants in this study highlighted that their brother/sister's cancer diagnosis reduced their access to play opportunities with their affected brother or sister as well as their parents. There were multiple reasons given for this, both the lack of time and importantly the physical and emotional changes in the child with cancer. Siblings play an important role as playmates, particularly in 'free play' which is child-centred play that is especially important for the development of creativity and imagination (Ginsburg et al., 2007; Tucker & Updegraff, 2009). Not being able to play with the child with cancer denied siblings these opportunities and appeared to have created a sense of loss. Given the important role of play in development, having play opportunities reduced is a significant detrimental consequence of childhood cancer not only for the child with cancer but also their siblings (Björk et al., 2006; Yogman et al., 2018). Siblings have an important bond and interconnection, act as playmates and confidantes, and help each other to develop social skills (Jambon et al., 2019; Tucker & Updegraff, 2009; Yogman et al., 2018). It would appear in this study the brother/sister's cancer treatment changed these roles and denied siblings the experience of 'normal' family activities and play.

Our study demonstrated that young siblings often expressed their feelings of fear and sadness to toys, inanimate objects, and animals. This appeared to be a common strategy used to help them process their emotions. Young siblings have the same desire as their older counterparts not to burden their parents with the additional worry about their emotions they appeared to rely on their imagination to provide them with an opportunity to talk about their emotions (Weiner & Woodley, 2018). Older siblings have been shown to use school and/or friends as an opportunity to express their emotions, which provides them with the ability to seek support (Bariola et al., 2011; Weiner & Woodley, 2018). The young siblings in our study did not highlight friends as a means of support, most likely due to their age and stage of development, where peers play less of a role in social support (Bariola et al., 2011). While talking to pets or toys is a common strategy that young children use to manage trauma, it does not provide children with the opportunity to access emotional support (Nabors et al., 2013). As observed by Salmon and Byrant (2002), young children often need adults/carers to process and cope with difficult experiences. In this study is would seem that childhood cancer and the inevitable absence of primary caregivers, coupled with a lack of peer-group support, may mean that young siblings do not have enough support to process their emotions.

Contrary to the findings outlined in previous research by (D'Urso et al., 2017) which reported that older 12–18 years siblings reported becoming closer to the child with cancer, this research found that younger siblings reported feeling that they had lost connection to their sibling. This may be a result of young children's cognitive development and their abilities to maintain bonds and develop new ways of communicating (Waters & Thompson, 2014). The major behaviour change resulted in a situation where siblings felt they had “lost” their sibling. Participants lamented the change in personality and frequently talked about how "their sibling used to be”.

Childhood cancer impacts the entire family, and in this study, siblings expressed that their relationships with their grandparents were altered. People sit within social systems with distinct roles within the family. Grandparents generally perform the "less strict roles", which have been described as "pleasure without responsibility" (Backhouse & Graham, 2011). Siblings expressed feelings of loss that grandparents who took on parental responsibilities were no longer performing their previous roles as grandparents. Childhood cancer treatment appears to have required families to redefine relationships and roles within the family (Van Schoors et al., 2021). Siblings in our study expressed sadness that they were not able to spend time with their parents (predominately mothers). This aligns with existing studies on the absence of parents as an area of concern (Weiner & Woodley, 2018). In contrast to previous studies with older sibling, participants in this study did not reflect that their families became closer (Prchal & Landolt, 2012). This may be because younger siblings with less cognitive skills are less able to process the changes to identify positives in their family’s dynamics.

The COVID-19 pandemic had a major impact on children and their family's receiving treatment for cancer. Research has highlighted that for some parents the COVID-19 pandemic provided advantages in reducing the risk of the child with cancer due to infection control measures and improving access to remote working (Davies et al., 2022). However, for siblings it would appear there were few advantages and the COVID-19 intensified feelings of loneliness and increased the time away from parents and siblings. Siblings also expressed that it exacerbated the fear of infection and reduced their ability to attend events and school.

Societal representations of childhood cancer appeared to have impacted how young siblings responded to the cancer diagnosis. Siblings explained that their knowledge of childhood cancer was impacted by societal representation acquired through the movies and social media. This informed their responses to the diagnosis, with those who had been exposed to these mediums fearing that their sibling would die. Vygotsky's social-cultural theory posited that children's knowledge is socially constructed, a notion that emphasises the importance of the social environment (Bozhovich, 2009). Siblings' understanding was influenced by media and social representations of childhood cancer. Societal gender roles also appear to have impacted how siblings responded, with several male siblings expressing that talking about emotions was not acceptable. Differences in responses to trauma have been shown in previous research, with girls showing more internalising behaviours and boys exhibiting externalising behaviours such as aggression (Skybo et al., 2007).

Limitations and future research

Limitations mainly pertain to recruitment strategies. Convenience sampling and the necessity to recruit via the parents/carers meant parents were adult gatekeepers to participation in the study and children needed their parents to be interested in participation before they were given details (Punch, 2002). This may have also impacted the selection of participants as parents had to be confident about their children’s ability to articulate their feelings thus those children with poorer communication skills may not have participated. Our study was also conducted during the COVID-19 pandemic, which may have increased the sense of isolation that siblings felt due to hospital restrictions. The COVID-19 pandemic might have also limited access to camps and other support services that normally assist siblings of children with cancer and facilitate family reconnection (Davies et al, 2022). In a multicultural society, research needs to include families from different backgrounds. Our study had only one family from a culturally and linguistically diverse (CALD) background. There was also a mix of younger and older siblings (in terms of birth order) than the child with cancer. It may be that birth order may impact the experience and it may be useful for future studies to look at these two distinct groups. In addition, while this study expanded knowledge to look at a young cohort (8–12 years), it may be useful to expand this to those between 6–8 years by using strategies such as drawing and play to gather their perspectives.

Clinical implications

Our study highlighted the need for family-focused healthcare that acknowledges the varying needs of children of different ages. While guidelines do exist to support siblings, previous research has highlighted that support provided to siblings does not meet their needs, and comprehensive and developmentally appropriate supports need to be provided (Davis et al., 2023). This study provides a better understanding of younger siblings' experiences. One important aspect explored in this study is younger siblings' reliance on toys and pets to manage their emotions. This emphasises the differences in how children of differing ages adapt to the experience. Given young children's affinity with games/toys, it may be useful for these to be used by healthcare professionals or parents/carers to help young children to discuss and explain their emotions and responses when their brother/sister is diagnosed with cancer (Salmon & Bryant, 2002). Younger siblings interpret the diagnosis depending on their existing knowledge and life experience. It is therefore important that at diagnosis discussions are held with siblings regarding their understanding of cancer so that appropriate information can be provided. Parents have been shown to lack awareness of the extent of siblings' emotional responses to the childhood cancer diagnosis and treatment (Pariseau et al., 2020). It is recommended, therefore, that parents/carers are provided with information regarding how younger siblings may respond to the cancer diagnosis and treatment. This may assist parents/carers to be able to provide the appropriate support according to their developmental needs.

Overall, it could be beneficial for allied health teams to provide healthcare professionals with information on how younger siblings may respond to being told about the cancer diagnosis and the potential for misunderstanding. This may help HCP support parents in disclosing the diagnosis to younger siblings. It would be helpful for healthcare teams to be given education/information on younger siblings' ability to process information. This will enable them to adjust support to meet younger siblings' needs. It is also necessary to understand the impact of the absence of the child with cancer, both emotionally and practically, and encourage measures to assist siblings to maintain bonds with the child with cancer—for example, providing opportunities for shared activity sessions.

Conclusion

The current study fills a gap in the research by exploring the impact on siblings aged 8–12 years. Children’s cognitive maturity impacts how they understand and process information. It is vital to gather more information regarding the losses experienced by siblings so that more support can be provided. Younger siblings are required to adapt to situations that adults find difficult to adjust to, with little acknowledgment of their emotional and cognitive skills and ability to understand childhood cancer. The findings of this study extend our current understanding by showing that young siblings' developmental and cognitive skills impact their experiences of childhood cancer. Siblings outlined the many losses they had experienced, which demonstrates a need for a more comprehensive and coordinated program to support young siblings of children with cancer. Providing support to siblings has the potential to improve their well-being, which ultimately supports the whole family.

Clinical recommendations

This research highlighted several areas where improvements can be made to support younger siblings when their brother or sister is diagnosed with cancer:

- Increase use of toys and games by HCP, families and play therapists to assist younger siblings to both explain the cancer diagnosis and for them to discuss their feelings and responses.
- HCP to be provided with information that younger siblings may experience childhood cancer differently to older siblings to enable them to develop appropriate support services tailored to younger siblings individual needs.
- Provision of education to parents by HCP to assist parents to understand how younger siblings may experience childhood cancer and to assist them to provide support.
- Development of strategies to assist siblings maintain contact with their brother of sister with cancer for example facilities to enable family dinner on the ward or opportunities to play so that younger siblings can maintain a connection to their brother of sister with cancer.

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CHAPTER 8 - Study 6: In their own words: Advice from parents of children with cancer

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Chapter overview

This chapter consists of an article exploring parents' responses to the final interview question, "What advice would give to parents whose child has just been diagnosed with cancer that you wish you had known when your child started treatment?" This question was included at the end of the interview to provide an opportunity for parents to reflect on what they had learnt from the process. During analysis, it was decided that this information would be of benefit to other families, providing first-hand information to parents to help them manage their child's cancer diagnosis and treatment. It is envisaged that information from this research article could be used to prepare information sheets for parents or discussed in peer support forums. It has been submitted to a *Journal of Pediatric Psychology* and minor changes have been recommended before final publication.

What this adds to the literature

This article sought to directly ask parents what advice they would have liked to be given when their child was initially diagnosed with cancer. This advice, gathered with the benefit of hindsight, could be useful in developing resources to assist families of children with cancer. Directly asking parents what they would have liked to know has allowed valuable and useful information to be gathered, providing clear recommendations for parents. This study provides important information for those involved in the care of children with cancer and their families and has the potential to improve outcomes for both.

Abstract

Background: Approximately~800 children are diagnosed with cancer in Australia every year. Research has explored their experiences and developed recommendations for improving support provided to families. These have included the provision of psychology services, improved communication between HCP and parents, and increased information for families.

Methodology: In our hermeneutic phenomenological study, forty-four participants (21 fathers and 23 mothers) ranging in age from 28 to 51 years (*M* = 37 years, *SD* = 5.6 years) were interviewed. Interviews ranged from 45 to 150 minutes (*M* = 65 minutes, *SD* = 18 minutes) in duration.

Findings: Thematic analysis of the data generated seven themes: "Take it second by second"; "Find some normality"; "Take care of yourself"; "You need to talk to someone"; "Just take all the help"; "Speaking up for your child"; and "Take care of the siblings".

Conclusion: The results of our study provide firsthand advice from parents. The overwhelming theme that emerged is that while many parents revealed that they had not asked for or received support, in hindsight they unanimously wished they had sought out services. The strength of this study is that parents are more likely to accept the advice of other parents with a shared lived experience. The results of our study can be used to develop resources that could be provided to parents. These resources would emphasise that the recommendations come from parents who have travelled the same path and have learnt from hindsight and experience.

A diagnosis of childhood cancer is a traumatic and distressing experience for the whole family (Molinaro & Fletcher, 2018). Parents of children diagnosed with cancer have demonstrated significant psychological distress, with nearly 80% of parents exhibiting moderate-to-severe post-traumatic stress syndrome (PTSS) after a childhood cancer diagnosis (Al-Gamal et al., 2019; Bally et al., 2014; Robinson et al., 2007; Sulkers et al., 2015). The efforts of the healthcare team and the support structures surrounding the family are concentrated on the child's treatment and recovery, often leaving parental needs overlooked (Cox, 2018; McEvoy & Creaner, 2022; West et al., 2015). This dynamic extends to parents themselves, with literature highlighting that parents often neglect self-care, sleep, and nutrition, which can further compound the negative psychological ramifications of childhood cancer (Cox, 2018; Davies & O'Connor, 2022; Santos et al., 2018). The diagnosis and treatment also cause a fundamental shift in parental roles and responsibilities, impacting multiple aspects of family life such as parents' income/working arrangements, friendships, and personal relationships (Cox, 2018; Patterson et al., 2004; Sultan et al., 2015; West et al., 2015).

There are differences in parents' experiences, with mothers exhibiting higher rates of anxiety, depression, and post-traumatic stress disorder (PTSD) than fathers (Kazak et al., 2005; Pai et al., 2007; Young et al., 2002). One potential explanation for these higher rates is that mothers typically provide more care in the hospital than fathers, and therefore, they experience more trauma from witnessing their child's treatment (Vrijmoet-Wiersma et al., 2008). Research has shown that fathers experience other significant stressors, including having to continue to work to support the family financially (Chesler & Parry 2001; Davies et al., 2023; Nicholas et al., 2009). Caring for a child with cancer is complex and demanding, requiring parents to juggle their child's medical care whilst also navigating normal familial roles. This experience may affect other relationships, including spousal relationships (Compas et al., 2015).

Rationale

Previous studies have focused on improvements to services for children with cancer and have made recommendations that can be implemented by healthcare professionals (HCPs) and hospitals. This research plays a valuable role in facilitating healthcare systems and clinicians to support parents. Family-centred care (FCC) is a model of care in which clinicians and families work in partnership to provide care that foregrounds the family's needs and well-being. This model of care has been increasingly promoted as a means of facilitating improved psychosocial outcomes; however, appropriate implementation relies on clinicians developing a nuanced understanding of the family's needs and experiences. This research seeks to bridge this gap by providing first-hand advice from peers who can provide suggestions and support based on lived experience which can complement FCC services (Hoey et al., 2008; Jablotschkin et al., 2022; Joo et al., 2022; Raharjo et al., 2020). To complement existing research, the present study focused on what parents believed they would have liked to have known at the beginning of treatment. We sought to directly explore parents' advice to other parents at diagnosis, to create resources to empower parents, and to complement existing support services. Grounded in an understanding of consumers as experts in their own experiences, we sought to foreground parents' interpretations of their need for support surrounding their child's diagnosis.

Methodology

Research design

Our study was part of a larger study that aimed to explore the lived experience of individual family members of children with cancer. We used qualitative research informed by a phenomenological framework that sought to understand what it was like to experience the phenomenon and allowed participants to provide descriptions of their feelings and impressions (Gallagher & Francesconi, 2012). Semi-structured interviews provided the opportunity for an in-depth exploration of participants' lived experiences (Dew, 2007; Hannum et al., 2019).

Participants

Participants were selected primarily by convenience sampling, with snowball sampling also used to ensure the sample consisted of a good cross representation for example families who lived regionally (Leavy, 2017). Our study recruited individual family members separately; for example, fathers were recruited in separate processes to mothers. We recruited mothers and fathers who had a child 17 years or younger who was currently receiving or had completed treatment within the previous 15 months with curative intent and who were able to converse in English. Stepparents, those in de-facto relationships, or any adult performing a parental caregiving role, including non-biological parents, were included in the study. Family members of children who were receiving palliative care were not eligible for participation.

Procedure

Ethical approval was obtained in March 2021 by the Curtin University ethics committee. Recruitment was completed in Australia between March and July 2021. Interviews took place during the COVID-19 pandemic. Study invitations were placed on hospitals' closed Facebook pages. Access to these pages was facilitated by JD's status as an inside researcher, having had a child diagnosed with cancer. Flyers with the study details were also distributed by various organisations that support families of children with cancer. Participants were also recruited via word of mouth, with participants sharing the study details with other parents.

An interview guide consisting of 15 questions was developed based on previous research and consumer input. After recruitment, JD contacted all participants to organise interview times. All semi-structured interviews were conducted either by teleconference (24) or at a location suitable to participants (20). All interviews were digitally recorded. Before the interview, participants were provided with study information, a consent form, and a demographic questionnaire. The demographic questionnaire contained questions regarding the child's cancer diagnosis and enrolment in education and the parents' work status. At the commencement of the interview, JD outlined the study information, reviewed consent, and explained that participants could pause the interview at any time or cease if they no longer wished to participate. During the interview, various questions were asked about the experiences of having a child with cancer, including the impact on their psychological well-being and family dynamics. The final question of each interview was, "What advice would give to parents whose child has just been diagnosed with cancer that you wish you had known when your child started treatment?" Once the interview was completed, all participants were thanked and given a list of support services and a $20AUD gift card.

Data analysis

Reflexive thematic analysis (TA) was employed to analyse data. TA belongs to the phenomenological research tradition, which focuses on participants' 'lived experiences' and how they make meaning from these experiences (Braun & Clarke, 2021). This study used Braun and Clarke's six-phase process (Braun & Clarke, 2022). The first step involved familiarisation with the data by reading through transcripts and taking notes on initial impressions. The second stage of TA involved systematic data coding. After reading transcripts, codes were developed using a manual paper-based process with codes attached in the margins. The third stage involved generating themes from the data and codes. The fourth stage consisted of reviewing early themes. To assist the fourth phase, a thematic map was developed to represent the findings graphically. In the fifth phase, all authors reviewed the themes to ensure that unnecessary themes were excluded and that there was sufficient data to support each theme. Names were given to each theme. The final stage involved the themes being written up into a report.

Quality & Rigour

To ensure rigour, this study followed the Consolidated Criteria for Reporting Qualitative Research 32-item checklist (Tong, et al., 2007). An audit trail was kept to record decision-making processes and the decisions made. JD was a PhD student with extensive qualitative experience within the oncology setting. JD was also an inside researcher, having had a child diagnosed with cancer at age 12. To ensure credibility, a reflexive journal was kept throughout the research process to record personal observations, thoughts, and responses to data to enable awareness of any personal reactions/bias and self-appraisal of JD's positionality (Berger, 2015).

Consumers (people with lived experience) were involved throughout the research process to ensure that the study was grounded in people's realities and that any documentation was sensitive, clear, and appropriate. The initial findings/themes and reflections were also discussed with our consumer representatives for their feedback and input.

Findings

The final sample comprised forty-four participants (n= 21 fathers and n=23 mothers), with ages ranging from 28 to 51 years (*M* = 37 years, *SD* = 5.6 years). Interviews ranged from 45 to 150 minutes (*M* = 65 minutes, *SD* = 18 minutes) in duration. Further participant demographics are provided in Table 1.

Table 1

Participants demographics (N=44 participants)

Parents demographics	Fathers (21)		Mothers (23)	
	N	%	N	%
Location				
Regional	5	24	7	30
Metropolitan	16	76	16	70
Marital status*				
Married	18	86	18	78
De-facto	2	10	2	9
Stepparent	1	5	1	4
Single	0	0	1	4
Divorced	0	0	2	9
Educational level				
Year 10	0	0	3	13
Year 12	3	14	2	9
Tafe (trade college)	6	29	3	13

Bachelor	8	38	8	35
Postgraduate	4	19	7	30
Treatment				
On	16	76	15	65
Off	5	24	8	
Child's primary diagnosis				
Brain cancer	2	10	2	9
Sarcoma	4	19	3	13
Haematological	10	48	11	48
Neuroblastoma	3	14	2	9
Lymphoma	1	5	3	13
Other	1	5	2	9
Current work status				
Full time	18	86	1	4
Stay at home parent	0	0	5	22
Part time	1	5	4	17
Parental leave	1	5	6	26
Carer	0	0	6	26
Other	1	5	1	4
Changed work status **				
Yes	7	33	18	78
No	14	67	5	22
Siblings of child with cancer	N	%	N	%
0	3	14	1	4
1	10	48	13	57
2	6	29	6	26
3	1	5	2	8
≥4	1	5	1	4
Child in school at diagnosis				
Yes	10	48	7	30
No	11	52	16	70
Interview location				
Online	12	57	13	57
Workplace	3	14	0	0
Home	2	10	8	35
Childhood cancer family	4	19	2	9

Percentages may not add to 100 due to rounding.

**Two mothers were in same sex relationships but co-parented with father*

*** Fathers whose work status changed included work from home/hospital or change in schedules.*

*** 5 Mothers who did not change work status were on parental leave (government paid leave or were stay at home parents without income support)*

Seven themes were generated from the data during analysis, as described below.

'Take it second by second".

This theme reflects parents' advice to focus on the 'here and now' and not overthink what may happen regarding their child's treatment and outcomes. Parents observed that it was a traumatic experience and the only way to cope was "Don't look at what's happening ahead of you. Look at what is in front of you and then just deal with it." Many parents emphasised that the only way to achieve this was by not focusing on the big picture. As one parent described, "You've got to manage … I know it's very cliché, but it's taking it in small chunks. I should be giving myself this advice but it's really if you take it in small chunks." As one mother described, "Often it is just taking it second by second as you can't focus on anything bigger." Parents explained that this strategy helped them to carry on, "especially on the bad days". Within this approach, many also described the need to not plan too far ahead, as "You have to just expect the unexpected and yes, just roll with it, keep swimming." Several parents also described how they had initially tried to control and push against the situation, however, they learnt not to "fight it, just go with it, and just go through the motions because it's just too exhausting to do otherwise". Many reflected that they had not done this in the early treatment phase. For example:

> I regret that I spent so much time worrying about the what-ifs and all the bad things that could happen when so many things happened that we had no control over…so my advice would be don't do that even though it feels like the right thing to do, just take it in as it comes…focus on the here and now.

"Find some normality".

This theme describes parents' advice to try to maintain some sense of normality during treatment. Parents described how it was often hard to do things they usually did due to the unpredictability of treatment, but "the advice I'd give to mothers is try and maintain a little bit of a sense of normality". Many explained that they realised it didn't have to be big things, but for the sake of their kids (both siblings and the child with cancer), a sense of normality was important. "Even if it was just having a routine of a meal together … even if it had to be in the hospital … anything really, just some normal amongst the crazy." Some mothers reflected that the ability to try to maintain normality was obviously 'dependent on the diagnosis', reflecting "I think … maintaining a sense of normality. That's maybe hard to do. I know some people don't have as good a prognosis maybe as we did. Maybe that helped." Several parents whose children had aggressive cancers commented that, while they wanted to 'keep things normal', it was often "very difficult as I never knew what the shitty cancer was going to throw at us … but we tried to create the normal where we could even if it meant doing things differently to our old normal." For these families, it often meant adapting family routines so that small aspects of the old normal could be incorporated into their current situation. One family described how:

> Sundays [before cancer diagnosis] we always played board games as a family, normally Monopoly or Scrabble … [child with cancer] was often too sick to play so about halfway through treatment we just started playing simpler games that didn't need thinking … that way we had our normal routine … it made us feel like life went on even if it was just a small thing.

This strategy of maintaining some sense of normality was seen to benefit parents by helping them to cope, but it also helped children. “I think that sense of normality was good for [child with cancer] as well. Not feeling pandered to, feeling like there were still normal things going on made him feel things would get better.”

“Take care of yourself”.

This theme explores parents’ thoughts regarding self-care and the need to prioritise their physical health. This was a theme most commonly highlighted by mothers rather than fathers. They frequently commented that, in hindsight, they did not take care of themselves or their health during treatment. “I know I didn’t … I didn’t eat well … I didn’t sleep well … I didn’t basically do anything for my own self-care and after a year of that I was a complete mess.” Many mothers reframed the need to take care of themself as ultimately helping the child with cancer, with one mother stating:

> Don’t forget to take care of yourself because yourself is going to be the most important thing for your child. If yourself is not right or healthy, or happy, then the child would absorb all of that. Taking care of yourself, it’s somehow taking care of your child.

Similarly, another mother explained, “But you have to look after yourself first. Or you can’t look after your children. “Fathers more commonly recommended other parents seek healthy coping strategies. Several fathers observed that using alcohol to cope.

> … doesn’t really help … and just makes you feel worse … I know my wife found it hard and was worried about my alcohol use … I had never been a big drinker, but I just used to go home and drink to escape.

Fathers reflected that this impacted their physical health and “drinking that much was shit for my sleep and everything … so bad for my health in the long run.” Parents observed that it was hard to take care of yourself “when everything was so shit” but they noted that it was a long process and to ensure they could keep going “you have to at least give yourselves the basics [food and sleep]”.

“You need to talk to someone.”

This theme explores parents’ perceptions that they wish they had sought out psychological/emotional support during their child’s cancer treatment to help them manage the emotional toll of having a child receiving cancer treatment. Several parents reflected that it was not possible to manage the stress on their own and that they really should have reached out to discuss and talk about their emotions. As one father observed:

> You need to support, everyone needs support … someone to talk to. If you need support, ask for support, and talk to people … We [fathers] have this macho thing of, ‘I don’t need help, I don’t need help.’ No, we all need help in a way.

Notably, this was advice was frequently given by fathers who were asked during the interview if they had sought psychological/emotional support. All fathers (n = 21) indicated that they hadn’t and “thought they could do it on their own”. In hindsight, they reflected “that I wouldn’t be in such a bad place now if I had known I should talk to someone … so yeah, if I could tell dads one thing, it would be to seek someone to talk to". Parents had different perceptions of who was best to seek support from. Some reflected that it required professional support. "Talk, and not necessarily to other parents, but to social workers, psychologists, whatever … you will feel better for it." Several noted that it was best to have professional help from "mental health workers who understood … though that can be hard to find … you need someone who you can just talk to about how hard it is without having to explain everything". Other parents reflected that it was best to talk to other parents who had been through similar experiences. "I would tell them to seek out support from people who have been through it, as well as anything at the hospital where there's a group of parents, they know each other, just so you have that support." Parents explained that only other families "can share the pain that you're experiencing, so talk to them".

"Just take all the help".

This theme outlines mothers' and fathers' advice regarding accepting and seeking practical support such as meals, gardening, and housework. As one mother explained:

> Just say yes if someone else offers to cook something. So, I … take what it is when someone offers to go pick up groceries or food … because at the start I felt really bad about accepting help … I was an idiot.

Many recalled how at the beginning, they were reluctant. "People offered to help, and we go, 'Oh no no, it's okay. We'll figure it out' … that then leads to burnout and carer's fatigue … ask for help with anything you need." Some parents also noted that the child's cancer diagnosis affected the whole family, and they hadn't realised this at the beginning. Accepting practical support from family also helped them process the experience:

> I learnt that it's not necessarily an imposition to take support from your family members. I used to feel very guilty if someone in my family was to help me, that I was actually doing the wrong thing because it would be too tiring or too hard for them, too much of an imposition. Whereas now, I realise that it's just part of the family, that's what they want to do, and it might be harder for them if you don't let them help you, so just take all the help.

Parents reflected that accepting help was important to enable parents to be able to focus on their children and their needs. As one father observed, "We said no to some help, which was stupid … because taking that help [household-related work] would have given us more time to help [sibling]." Notably, the advice to accept help generally revolved around getting help for the family rather than individual help to support the parents. Most participants noted this phenomenon of initially refusing help, but in hindsight wishing that they had accepted help from the beginning, and firmly recommending that new families learn "not to do what I did … accept the help".

"Speaking up for your child".

Many parents highlighted the need to 'advocate' or speak up for their children. This theme captures parents' perspectives on this topic. Parents described feeling, at the beginning of treatment, that they "couldn't make a fuss or be too demanding," but that in hindsight they wished they had. As one parent observed:

> You have to learn how to advocate and really ask for things because you're not going to get told … Yes, you need to ask for things, and you need to stand up for your kids. You need to learn the system and the rules of the system and then use them to your advantage when you can.

One issue that was commonly used as an example was obtaining vascular access, with parents describing:

> I used to just sit there and watch them hurt her … I knew it wasn't going to work as it never did when they did it that way … I feel so bad I didn't speak up and tell them how it should be done … I'm her mum, it was my job to speak up for her.

Both mothers and fathers raised this as an issue, stating that in hindsight they wish they had done more and emphasising that "if you are not happy about things, then speak up about it." Parents reflected that "You shouldn't worry if people like you or not…that's not the important thing…being your kids' voice is the important thing."

"Take care of the siblings".

This theme reflects parents' observations that it was important to take care of all their children. Many noted that they hadn't done this amidst the trauma of caring for a child with cancer; for example, stating that "We just let everything slip and the others missed out on so much." One mother described how she realised part-way through treatment that the siblings were not getting the support they needed: "[I] really had to make sure that I had to divide that time up between the five of them. And it was a bit of a juggle … but so needed." Parents reflected that it was often difficult, but that the siblings shouldn't "have to pay the price for all of this shit". Parents reflected that towards the end of treatment, they noticed the impact on siblings:

> [Brother of a child with cancer] is so upset … he has changed so much … not the happy kid he used to be. He is so angry with everyone … but I feel guilty … because I know we just forgot about him … well, not forgot, but we forgot he had needs … to do again, we should have thought about how it affected him … I'm not sure how we are ever going to make it up to him … yeah that is what I would say to other dads … take time to think of all your kids.

This aspect was one that most parents reflected on and discussed that they wish someone had told them at the beginning to "to try to make some time with siblings". They were not always sure "they would have been able to do the care themselves like it used to be," but that they should have found some way to let siblings know they were "still important". They noted that this would have made a big difference to their family, and they felt "others should know and learn from their experience".

Discussion

This qualitative study aimed to develop an understanding of what advice parents would give to other parents of children newly diagnosed with cancer in navigating the complexities of a childhood cancer diagnosis. We sought to develop recommendations that could be provided to parents of children who have recently been diagnosed that were grounded in the lived experience of parents.

We observed that a loss of normality was a major issue that impacted parental well-being, and that they missed that sense of ‘normality’. Definitions of ‘normal’ inevitably vary between different people, but it can be defined as any behaviour or condition that is usual, expected, typical, or conforms to a pre-existing standard (West et al., 2015). In the context of childhood cancer treatment, ‘normal behaviours’ are not possible as parents must adjust to the treatment cycles and life within the hospital environment (Björk et al., 2005). To address this, parents advised that the only way to reassert a sense of normality is to create their own new ‘normal’ by establishing new routine behaviours and practices. This study underscores the importance of normality and the vital role it plays in parents’ well-being and familial cohesion (Rost, 2021). In the current study, parents recommended that old routines be adapted, and new behaviours forged as a family, which would facilitate the development of a sense of normality.

Parents reported that they struggled with living in a constant state of uncertainty, where circumstances could change from minute to minute. Uncertainty has been shown to create feelings of both anxiety and distress, while having a sense of what to expect gives people a feeling of security (Nikfarid et al., 2017; Rost, 2021). The nature of childhood cancer treatment, which often entails unexpected hospital admissions due to infection or various treatment side effects, means that having a predictable plan or schedule can be nearly impossible for families. Parents suggested that to help deal with this uncertainty where things change so unpredictably, parents should focus on the short term, as this strategy helped alleviate some of the stress and anxiety. Parents also reported that they worried about how they might be perceived by HCPs. However, with the benefit of hindsight, they emphasised to other parents that their role as parents was to advocate for their child and not worry about what others thought of them.

Aligning with previous research, parents in our study observed that they did not prioritise their health or take care of their most basic healthcare needs such as sleeping and eating well (Davies & O'Connor, 2022; McEvoy & Creaner, 2022; Ozdemir Koyu & Tas Arslan, 2021). This was more pronounced for mothers than fathers, with mothers tending to emphasise that they wished they had focused on their basic health needs, whereas fathers tended to describe unhealthy coping mechanisms (McEvoy & Creaner, 2022). This distinction may reflect that mothers spend more time on the ward and thus cannot access adequate nutrition and sleep. Research has found that parents—and mothers in particular—feel that they must focus on their children and often neglect their own needs (Davies & O'Connor, 2022). As the present study shows, parents ultimately realised that this was not in their or their children's best interests and they observed that taking care of their physical health had benefits for not only themselves but also their children. Research has found that parental and child health is interconnected, with children having better outcomes when their parents' health and well-being are improved (Kearney et al., 2015). Parents reflected that that this understanding was not apparent at the commencement of treatment, and often the realisation followed the negative effects of not focusing on their well-being. They therefore recommended that parents remember to take care of themselves as it ultimately benefited their children.

Parents recommended that other parents access psychological support systems. Many noted that they were very reluctant to do this at the beginning and, in hindsight, they felt that this had significant negative effects. Psychological support has been shown to lower levels of parental distress (Bennett Murphy et al., 2008; (Wiener et al., 2015). Our study raises an interesting issue: while it is widely accepted that parents need to be provided with psychological support, and many health systems are working to provide more support, many parents do not ask for support as they feel they need to be able to manage on their own. This may be a barrier to seeking support. Therefore, the provision of psychological support must be proactive and encourage parents to access psychological support by emphasising that this is a recommendation by other parents of children with cancer. Parents in our study also suggested that parents should actively seek emotional support from less formal mechanisms, such as peer support from families who have experienced childhood cancer. This finding underscores the importance of peer support services that provide families with varying forms of support to meet parents' needs.

The diagnosis of childhood cancer causes substantial shifts in family dynamics, with a change to a patient-centred family (West et al., 2015). Parents in our study reflected that early in treatment, they focused all their energy on the child with cancer. However, they felt that while this was inevitable, it was not in the best interests of the family unit in the long term. Siblings experience significant impacts when their brother or sister is diagnosed with cancer. Parents in this study observed that it was often in hindsight that they saw the 'damage' caused by inadequate attention to the siblings (Porteous et al., 2019; Van Schoors et al., 2019; Weiner & Woodley, 2018). Therefore, parents in this study urged that future parents of children with cancer remember to provide care to their siblings as well. Parents will inevitably feel guilty about the impact on siblings and, in the stress of a cancer diagnosis, receiving advice from other parents with first-hand experience may enable them to view this as less of a reflection on their parenting skills, but rather as helpful advice to prevent future issues.

Limitations and future research

While this study provides useful information on advice that parents wish they had known when their child was diagnosed with cancer, it has some limitations. While the sample size was appropriate for a qualitative study, the sample did not adequately represent parents from varying cultures and ethnicities, with most participants being drawn from English-speaking backgrounds; this reduced the generalisability of our study. Attempts were made to recruit participants from culturally and linguistically diverse backgrounds via snowball sampling, but the number of families being contacted declined, with most citing issues regarding language. Future research would benefit by incorporating translation services so that perspectives of non-English speaking backgrounds could be included. Furthermore, it would be beneficial if a more detailed examination was obtained of how parents would suggest programs be implemented to support both themselves and their children. It would also be useful to explore if there are differences in the experiences of parents at differing stages of child development; for example, parents of teenagers may have different experiences, particularly about education.

Implications

This research highlights the need for parents to be provided with firsthand information from other parents to support them in managing the complexities of childhood cancer. Much of the information gained from this study could be provided in easy-to-read infographic materials, with an emphasis that this advice is not from HCPs but from other parents with lived experience. Previous research has suggested that HCPs are best placed to encourage parents, and mothers in particular, to take care of their health and well-being (McEvoy & Creaner, 2022). However, while HCP advice and support are beneficial, it may also be helpful for parent advocates with lived experience to inform parents of the need for self-care. It may be useful to emphasise to parents early in the treatment that other parents of children with cancer recommend good self-care, as it ultimately improves outcomes for their children. These findings may act in concert with a holistic model of FCC, with clinicians using the understandings gained from this research to facilitate partnerships with families.

There are many aspects of support for parents of children with cancer that could benefit from the implementation of comprehensive peer support programs. For example, other parents are well placed to advise about managing feelings of uncertainty and the strive for normality, as they can empathise with these feelings. Additionally, peer support programs should inform parents that managing their psychological well-being will not only improve outcomes for themselves but will also benefit their children (Clawson et al., 2013; Molzon et al., 2017). In support of this conclusion, recent reports have found that peer support programs—that is, information and advice programs delivered by those with lived experience—are effective and successful (Campbell et al., 2004; Dennis, 2003; Edwin et al., 2015). Given the importance of a sense of normality, introducing programs that support families in developing normal routines, even if it is simple measures such as creating opportunities for family dinners, would be of value (Molinaro & Fletcher, 2018).

Conclusion

The strength of this study is that parents are more likely to accept the advice of other parents with a shared lived experience. While much has been written on the experiences of children with cancer and recommendations for changes to services have been developed, this is often theoretical and related to policy within the hospital system. In contrast, the results of our study can be used to develop resources that could be provided to parents. These resources would emphasise that the recommendations come from parents who have travelled the same path and have learnt from hindsight. It is envisioned that these resources would provide parents with practical and emotional advice that may help them manage the complexities of childhood cancer.

Clinical recommendations

- Provision of information to parents via infographic materials detailing the advice of other parents.
- Implementation of peer support by parents to provide firsthand advice to other parents.
- HCP provide encouragement to parents to ensure they take care of their own needs during their child’s treatment emphasising that it ultimately benefits the child with cancer.
- Support provided to families to consider the needs of siblings and ensure parents are provided with services to facilitate family engagement.
- Introduction of programs on the ward that help parents maintain a sense of normality including facilities for family meals.
- Education to HCP of the needs for families to access psychological support including explanations of parent’s reluctance to seek this support so that HCP can address and encourage parents.

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CHAPTER 9 - Thesis Discussion

Chapter overview

This final chapter provides an analysis of this thesis describing the overall impact of childhood cancer. It will outline the key findings of the published papers and will identify issues experienced by individual family members (mothers, fathers, grandparents & siblings) providing a discussion of the influence of social-cultural values and expectations on family members' experiences using the ecological model as lens. In summation, it will provide suggestions for improvements to services offered to families of children with cancer.

The research presented in this thesis provides a comprehensive exploration of individual family members' (mothers, fathers, siblings, and grandparents) experiences of childhood cancer. A total of 79 family members were interviewed for this thesis and asked to describe how a diagnosis of childhood cancer impacted them. Ecological systems theory was employed to facilitate an exploration of how their roles within both their family and society had impacted their reactions to the child's cancer diagnosis. This research demonstrates that people's roles within the social system affect their responses to the child's cancer diagnosis. It is essential to recognise that given the intricate interplay among various factors, identifying where individual experiences intersect with the ecological context can pose challenges (Bronfenbrenner, 1979).

Nevertheless, this discussion aims to elucidate the principal insights from this research across the various ecological system levels.

In this study, all family members reported feeling distressed about the childhood cancer diagnosis. As previous studies have reported, the diagnosis of childhood cancer is difficult for family members to process and creates considerable fear (Bally et al., 2014; Compas et al., 2015; Cox, 2018). Family members faced substantial challenges in adjusting to the shifts in their lives resulting from the child's diagnosis of cancer. This research demonstrates that childhood cancer brings a shift in familial roles and responsibilities. It increases our understanding of childhood cancer by showing that each family member has clear roles and expected ways of behaving, shaped by gender, age, and societal norms, which are disrupted following a diagnosis of childhood cancer, which results in a requirement for family members to adjust multiple aspects of their lives This provides valuable insight into the experience which can help HCPs provide more targeted support for individual family members.

Mothers

This study revealed that normative gender roles appeared to shape mothers' responses to their child's diagnosis. Recent decades have heralded a shift in mothers' roles within the family, with fathers becoming more involved in the care of children (Banchefsky & Park, 2016). However, it would appear after a childhood cancer diagnosis, traditional gendered roles with mothers providing the majority of care still exist (Bennett Murphy et al., 2008). Previous childhood cancer research has explored caregiving roles and demonstrated that mothers provide most of the care when their child is diagnosed with cancer (Katz et al., 2018; Lewandowska, 2021). Existing research has, however, not explored the reasons why mothers provide most of the care or how it impacts family dynamics. This study builds on our understanding to demonstrate that this 'traditional' caregiving role is accepted as necessary, with mothers gravitating towards the caregiver role due to gendered roles in the family which are accepted by both parents.

Mothers in my study appeared to have internalised the perception that they needed to prioritise their child with cancer from the outset to the exclusion of all other priorities, including their own well-being. This is consistent with existing research that has reported that mothers neglect their health (Clarke et al., 2009; Katz et al., 2018; Lewandowska, 2021; McEvoy & Creaner, 2022). This study highlights the extensive ramifications of this dynamic, showcasing how lack of self-care extends to expectant mothers. The topic of pregnancy and childbirth has mainly remained unexamined in prior literature, possibly due to studies frequently employing mothers as representatives of the entire family's experiences, thus overshadowing their distinct voice and their pregnancy experiences (Ljungman et al., 2016; McKenzie & Curle, 2011; Sundler et al., 2013).

Mothers who were pregnant when their child was diagnosed with cancer reported not focusing on essential pregnancy care. Societal discourse and normative roles suggest that women should sacrifice their needs to care for their children, including their unborn children (Baxter et al., 2015; Stevens, 2015; Sutherland, 2010; Young et al., 2002). During pregnancy, women adapt their lives to focus on caring for the unborn child, such as adapting their diet and refraining from alcohol and caffeine (Homer, 2016). This focus on the unborn child, however, was challenging for mothers in this study as the impetus to sacrifice everything for the child with cancer took precedence over the need to care for the unborn child. This created tensions for some women as they tried to reconcile the notion of the "good mother" who cares for children equally with the need to care for a child with cancer (Sutherland, 2010). These expectations, learnt from social norms at the macrosystem level and reinforced at the microsystem level, caused distress for pregnant mothers as they juggled demanding gender roles and conflicting demands. The exploration of this issue provides a critical understanding and reveals a significant need for more support for pregnant mothers of children with cancer.

In line with existing research, my study found that childhood cancer disrupted mothers' vision of their lives (Young et al., 2002). This appears to permeate all facets of motherhood, with mothers describing an individual shift and a disruption of their vision for their children's lives. This study explores a topic previously not examined to demonstrate that childhood cancer challenges the vision of their child with cancer, but also that of their unborn child and the vision of their lives as a pregnant woman. Pregnancy is a sensitive period steeped in cultural and social expectations, reinforced within various levels of the ecological model through popular culture and family constructs (Kennedy et al., 2018; Hamada & Matthews, 2019). Pregnant mothers appeared to have experienced intense feelings of biographical disruption as they tried to reconcile how to envision their pregnancy and the life of their unborn child while having to care for a child with a life-threatening illness. It changed how they viewed their future and their role as mothers to the unborn child. This tension between the different expectations and roles created distress at the individual level for pregnant mothers.

Fathers

Cultural parenting roles also appeared to impact how fathers responded to the childhood cancer diagnosis. In this study, fathers expressed the need to step back and allow mothers to fulfil the primary caretaker role. When describing why they adjusted their roles, fathers expressed that they felt it was necessary and that these “traditional” roles benefited both the child and the mother. As discussed above, research has shown that mothers provide most of the care within the hospital (Katz et al., 2018) and this may be due to mothers preventing fathers' involvement, with research reporting that fathers often felt excluded from participating in the care of their children (Hill et al., 2009). Previous studies have failed to explore fathers’ experiences or how traditional gender roles have shaped their experiences. Research has often focused on fathers having to combine work and caring for their family. In this way previous literature have in some ways been shaped by societal gender roles with research framed around father’s traditional roles as providers of financial support rather than the emotional impact of childhood cancer. This thesis adds a fundamental understanding to father’s experiences by exploring these gender roles. It shows that mother's role as primary caretaker (with fathers taking a back seat) resulted from the the father’s belief that they needed to accommodate traditional roles. These gender norms ostensibly appear to be communicated by individuals acting within the microsystem, as most fathers outlined, which just seemed to be the logical thing to do. Thus, these roles seem implicitly shaped by societal conceptualisations of gender and parenting roles (Banchefsky & Park, 2016). Notably, these roles also appear to be reinforced by others within the family's social system, with fathers observing that they received views from family and friends that it was the mother’s role to care for the child. This underscores a complex, self-reinforcing dynamic within the ecological spheres whereby understandings and expectations at each level are communicated to more proximal and distal levels, amplifying these understandings.

Fathers also tended to highlight their shift towards, or reinforcement of, a leadership role, where their focus was on caring for the family unit. In my research, fathers described feeling extremely distressed but also felt that they could not express these emotions as their role was to be the strong head of the family (Bennett Murphy et al., 2008; Brody & Simmons, 2007; Neil-Urban & Jones, 2002; Nicholas et al., 2009). This concurs with a previous study by Chesler and Parry (2001), which reported that fathers sense they need to be strong. Interestingly, despite shifts in societal norms over recent decades, these social messages are still prevalent, and fathers expressed they could not show any sense of weakness, which was reinforced by external sources (Banchefsky & Park, 2016; Borgkvist et al., 2020). Fathers often highlighted how this tendency not to demonstrate emotion caused tensions within the parental relationship, adding to the overall distress experienced by the family unit.

Despite the apparent drawbacks of fathers' stoicism, fathers nonetheless considered it a necessity. As fathers explained, these perceptions were not just implicit understandings from internal learned roles, but often, these expectations were explicitly communicated by friends, family, and HCPs. Consistent with the ecological model, those who communicated these external messages are themselves subject to broad societal understandings of gender roles, and therefore, gender roles appear to be self-reinforcing (Darling, 2007). Thus, we can see that sociocultural gender roles influence how fathers can express their inevitable distress associated with childhood cancer (Reis et al., 2017). By understanding how this sense that they needed to be strong was a product of both internal and external forces, we can provide support to families that enable fathers to access the social support they need and manage the tension caused within the parental relationship.

Fathers expressed that childhood cancer disrupted their expectations for life and their role in the family, making it difficult for them to align their roles with the harsh realities of the disease. One aspect that fathers found challenging to reconcile was having to witness their children experiencing painful treatment. Existing studies have often not explored in in depth fathers' responses to aspects of treatment. Many fathers in my study conveyed that they found it hard to be involved in treatment and explained that this was not something they felt prepared to deal with. Society often constructs fathers as providers and protectors (Fleming, 2004; Nicholas et al., 2016). In my study, fathers described a sense of frustration, feeling that they should be able to shield the child from harm, and described feeling helpless as it disrupted their view of their role in the family. As with other aspects, this sense of needing to be a protector of the family unit was both an internal perception and reinforced by external sources (Anderson, 2010; Möller-Leimkühler, 2002). We can thus see that behaviour and responses are shaped by the interplay of personal feelings and societal constructs reinforced within the microsystem and exosystem. As fathers generally have often taken on this protector role, it can be suggested that HCPs and those around them may fail to acknowledge the negative impact, and fathers are often not provided with the support they require.

While there were differences in how fathers and mothers responded, there were also a number of notable commonalities. A common issue highlighted by mothers and fathers was that the diagnosis meant they had to develop a new 'normal'. This aspect has been reported in other studies, which have concluded that families need to construct a 'new normal' that incorporates changes in identity, relationships, and expected behaviours (Arruda-Colli et al., 2018; Björk et al., 2005; Lewandowska, 2021; Nolbris et al., 2007; West et al., 2015). Parents ' responses to their lessons highlighted the importance of a sense of normality and what they would like to advise other parents. Normality, or a sense of it, was seen as fundamental to their ability to cope.

Grandparents

In common with mothers and fathers, grandparents (Evandrou et al., 2020) described feeling distressed at the disruption to their vision and sense of how life should be. Concurring with existing studies, grandparents outlined how distressing it was to try to process that their grandchild had cancer (Charlebois & Bouchard, 2007; Moules et al., 2012; Wakefield et al., 2014). Grandparents spoke of distortion to the natural "order of things" (Engman, 2019). They appeared to have a vision of how life should be acquired from their own experiences and perceptions of broader society. For grandparents, this revolved around the expectation they would be the ones who would become ill and pass away before their grandchildren. Analogous with fathers, grandparents also expressed a sense that witnessing their grandchildren experiencing painful treatment was impossible to reconcile with how life should be. This sense of disruption was a significant source of anxiety for grandparents.

One major area of disruption was the change in roles within the family that was caused by the child's cancer diagnosis. Many grandparents in my study modified their roles, adopting a more parental role in caring for the siblings, thereby shifting grandparents proximally within the ecological system, moving them closer to the nuclear family (Backhouse & Graham, 2012). Wakefield et al. (2014) found that this role change caused anxiety for grandparents as they negotiated how they would perform these new roles while still being able to perform the role of grandparents. They experienced childhood cancer as both grandparents, parents, and, in some cases, children of parents. Each of these roles carries different demands, placing grandparents in a uniquely distressing situation (Wakefield et al., 2017). Grandparents dually perceived their usual roles as playing a protective role towards their adult children with a sense that they should be able to protect them from pain, and an indulgent and less disciplinarian role towards their grandchildren. Childhood cancer meant that grandparents felt that both roles were distorted. Interestingly, many of the emotions expressed regarding the feelings of not being able to protect the families from distress were similar to those of fathers. Grandparents could not protect their adult children from pain. In addition, they now had to take the disciplinary role of caring for siblings. Grandparents appeared to understand the role grandparents should perform acquired from social constructs and normative roles.

In this study, the normative gender roles and expectations appear to have permeated across generations, with grandmothers detailing how they grappled with intergenerational caring responsibilities for their adult children, their grandchildren, and elderly parents (Fingerman et al., 2011). This need to care for multiple generations is increasing and research shows that consistent with gendered caring roles in society, this intergenerational support is more commonly provided by women (Evandrou et al., 2020; Fingerman et al., 2011). Previous studies have often not considered grandparents roles caring for multiple generations and generally focused on their roles within the child with cancer family. This study expands our understanding of grandparents' experiences, showing that due to the ageing population, grandparents must care not only for children and grandchildren but also for older generations. Grandmothers shared with mothers the belief that they ought to direct their efforts towards others, irrespective of how it might affect their own lives, with grandmothers observing that the new roles meant they ignored their health care and well-being. This study adds to our understanding to demonstrate that many of the experiences encountered by mothers regarding caring roles are replicated by grandmothers, highlighting that support should also be provided to grandmothers to acknowledge their conflicting demands.

Siblings

Siblings also appeared to have a concept of how their lives should be, encompassing certain expectations around family roles and what they could expect during their childhood. Research has highlighted that childhood cancer creates many losses for siblings, including less time with parents and changes to school life (Long et al., 2018; Weiner & Woodley, 2018; Woodgate, 2006). However existing studies have included a broad range of ages which has meant that the younger siblings experiences have not been explored in detail including the importance of time to play with their siblings. In this study, younger siblings expressed empathy for their affected sibling, but also sadness regarding the side effects, such as changes in personality, which hindered their ability to play together. Most siblings framed the experience around how it impacted their normal life. They appeared to have a vision for their lives and expectations, including time for play with siblings, time with parents, and fun activities such as birthday parties. This implies an implicit expectation of how childhood should be and a sense that they had lost normative childhood experiences, such as playing with siblings, which caused distress. Furthermore, siblings can be conceptualised as being isolated from their ecological system, missing out on time with those within the microsystem, such as their siblings and parents, and the exosystem, such as sports and social gatherings. Siblings appeared to feel this loss acutely and experienced sadness and anger in response.

The emotional development of siblings was crucial in how they perceived these changes. Younger siblings appeared to express a sense that they wanted life to be as it was before, and while they understood things had changed, they mourned the loss of their old life. Previous research exploring siblings' experiences has shown that older siblings did not express resentment about the losses they experienced (Tasker & Stonebridge, 2016; Van Schoors et al., 2018). This research is important and by focusing on younger siblings we have broadened our comprehension by revealing that younger siblings, owing to their development stage, tend to yearn for the old "normal life" instead of adapting to a "new normal", which is evident in adult participants. This most likely relates to their cognitive stage of development and ability to comprehend the changes occurring (Pons et al., 2004; Salmon & Bryant, 2002). This raises an important issue showing that sibling, and people in general, are a product of our life stage and social contexts. This highlights that support provided to younger siblings needs to acknowledge these differences and be tailored to meet their life stage and social contexts.

My study provides insight into gender roles, showing that siblings aged 8 to 12 years also exhibited gender roles, with some brothers reporting not wanting to talk about their emotions as it was not perceived as masculine and sisters expressing that they felt an obligation to care for other family members. Research shows that children adopt gender roles from a young age (Baker et al., 2016; Bussey & Bandura, 2004; Pomerantz et al., 2004). This was evident in this study, with siblings demonstrating gender norms with females focusing on caring and males' reluctance to express emotions. This lends further credence to an ecological understanding of familial responses to childhood cancer and underscores the need to conceptualise childhood cancer as being influenced by social influences and norms.

It is apparent that normative roles from the macrosystem level persist in shaping aspects at the individual microsystem level. This effect was most evident for mothers and fathers, however also extended to impact siblings and grandparents. The differences between mothers and fathers' responses appear to have largely centred around a reversion towards traditional gender roles for both mothers and fathers. All individual family members' roles shift after a cancer diagnosis, with mothers moving more proximal to the child with cancer based on traditional gender roles. Whereas fathers shifted their roles to focus on leading the family. Similarly, grandparents' roles also change as they amend how they function to accommodate caring for all family members from multiple generations. This underscores the influence of broader ecological and societal influences, and potentially reflects a strengthening of pervasive and implicit societal patterns in times of stress (Anderson, 2010; Bussey & Bandura, 2004).

Exosystem (please refer to Figure 2)

While there were differences in each family member's experiences, one aspect in which all family members expressed significant disruption was at the exosystem level regarding wider friendships groups workplaces and recreational interactions. This is consistent with previous research, which has demonstrated that childhood cancer significantly impacts families' friendships and social connections (Al Omari et al., 2021; Archibald et al., 2021; Kahriman et al., 2020; Kearney et al., 2015). This study further expands this understanding by highlighting neutropenia's pivotal role in reducing social engagement. It has often been attributed to the need to focus on the child with cancer and the lack of understanding by others in the community. In this study, family members feared the spread of communicable diseases, as seemingly benign infections such as the common cold or flu could have significant impacts on their child with cancer. This necessitated that all family members alter their social interactions to varying degrees, which was influenced by the role's family members were expected to perform. For fathers, it meant that their caring role for siblings was increased as they tried to reduce exposure to others, whereas for pregnant mothers, it hindered their ability to access support and services both during and after their pregnancy. The fear of neutropenia also extended not only to the nuclear family but also to the grandparents, who altered their social interactions to protect their grandchildren. Emphasizing their role as carers, they also noted that they felt guilty that they could potentially infect their grandchild with common colds and illness.

Siblings highlighted this as a significant area of loss, and they missed being able to participate in sport activities, camps, and community groups. Engaging in play and social interaction is crucial for young children, offering essential chances to develop social and motor skills (Ginsburg et al., 2007; Yogman et al., 2018). The inability to access these opportunities raises questions about possible adverse effects on young siblings. A novel finding of this study was that newborn siblings also missed opportunities for socialisation, with mothers reporting that they do not take newborn siblings and young toddlers to local playgroups and other recreational events for fear of infecting the child with cancer. Given the potential for interaction with social networks to buffer distress, it appears that all members of the family missed out on potentially valuable sources of support due to fear of contagious illness. This emphasises that the inability to access everyday interactions between the microsystem and exosystem can also influence experiences of childhood cancer.

Macrosystem (please refer to Figure 2)

My thesis demonstrates that the COVID-19 pandemic had far-reaching ramifications for families of children with cancer. This can explain how broad societal changes at the macro level can influence individual experiences (Bahn et al., 2020). COVID-19 impacted every facet of society, including education, work, finances, travel, and family interactions (Darlington et al., 2021; Murphy & Karp, 2020). This affected family members in a multitude of ways. In this study, mothers, fathers, and grandparents outlined that COVID-19 provided some benefits. One of the benefits outlined by parents was the increased availability of flexible or remote working, which reduced financial and time management stress, enabling work to be completed within the hospital setting (Brody & Simmons, 2007). Previous reports demonstrated that balancing working arrangements, which provided little flexibility while caring for a child with cancer, was a significant stressor for many families, especially for fathers (Chesler & Parry, 2001; McGrath & Huff, 2003; Robinson et al., 2019). The changes that occurred at the more significant societal level involving how work was constructed and where it could occur resulted in family benefits. This illustrates the profound influence that macro-level changes can have on individual experiences and for parents of children with cancer.

While COVID-19 did provide some benefits, parents in my study reported that restrictions and hospital visitation restrictions limited the social support at the exosystem level, making the experience more challenging. As previous research has shown, these supports are essential and assist families in managing the stress associated with childhood cancer (Melguizo-Garín et al., 2023). However, parents in this study found COVID-19 provided some comfort, as they no longer felt excluded as everyone was experiencing the same sense of isolation from social systems. This underlines that feeling part of the social system is vital in people's lives. Highlighting that all families will experience childhood cancer differently depending on their roles, siblings in this study revealed that COVID-19 only amplified their distress and increased their sense of loneliness from connections both within the microsystem and the ecosystem. It also disrupted their connection to their microsystem. As siblings expressed, they felt further away from their mothers and fathers and moved closer to their grandparents.

One way we can see a shared experience amongst all family members is how they responded to societal norms and attitudes toward grief and dying at the macrosystem level. Participants in my study reflected that they struggled with managing the grief associated with knowing children from other families on the ward who had died because of their cancer. Neimeyer et al. (2014) argue that death and the grief surrounding it are not just personal individual experiences, but social and cultural events. Attitudes to grief are socially constructed within broader social contexts at the macro level (Neimeyer et al., 2014). Harris (2010) argues that modern Western society is "death-denying" with little discussion, as it is often seen as a reminder of our own mortality. The death of a child may be considered even more taboo in modern Western cultures and is often seen as a reversal of the natural order of life (Harris, 2010; Vandenberg, 2001). For the mothers, fathers, and grandparents in our study, knowing other families whose children had died from cancer was thus confronting both on a personal and social level. This social taboo made it more difficult for participants to manage their reactions to the death of other children, as there is community reticence to engage in discussions about child death. For many families, this may be their first exposure to the reality of child death, and it may compound fears of their own child's mortality.

Attitudes to death and dying have changed throughout time, and modern society expects people to contain grief and death in private settings (Alam et al., 2012; Harris, 2010; Neimeyer et al., 2014). Thus, for family members exposed to the loss of a child on the ward from cancer, processing this grief was particularly challenging when messages were conveyed from broader society that they should keep their grief contained. My study has shown that the issues around grief only compound the sense of social isolation whilst also elevating their fear for their children (Harris, 2010). In this aspect, it is apparent that the context and culture surrounding family members can influence how individuals experience childhood cancer and how they process their grief.

Grandparents also appeared to experience this grief uniquely; despite a greater prevalence of dying and grief amongst their similar-aged peers, there was a perception that the death of a child was a violation of the natural order of things creating feelings of anger and guilt. Thus, grandparents still felt subject to similar societal taboos. This underscores the salient role that broader societal influences elicit on individual family members' experiences of grief and how this is stratified by age, gender, and familial roles (Tatterton & Walshe, 2019). Existing literature has shown that older siblings fear the death of a child with cancer (Nolbris et al., 2007; Woodgate, 2006). This study adds to this to demonstrate that even young siblings were aware of the mortality associated with childhood cancer. Young siblings described having learnt messages from media and popular culture that children with cancer die. It is therefore evident that even young children adopt messages from the macro level regarding what to expect when their sibling is diagnosed with cancer. Siblings also expressed the need not to discuss these thoughts of death with their parents, sensing—most likely from societal cues and norms—that discussing death and dying was taboo.

Clinical recommendations

My thesis findings indicate that additional efforts are required to assist individual family members in coping with the effects of childhood cancer. Many of these also need to occur at both the individual level such as changes by HCPs but also by structural changes within the health system. While more specific recommendations are outlined within the published papers, some broad commonalities across familial experiences merit further work to improve the provision of care to families of children with cancer. This study highlights that clinical care should adopt an ecological perspective, focusing on individual family members. HCPs must recognise each member's unique role within the family and society to ensure the support meets their needs.

One of the measures that can be implemented at the broader exosystem level by governments/health systems is the improvements in data collection. One of the issues faced within paediatric research and delivery of support services in oncology is that data on the composition of families are often limited. Researchers and service providers often need to be extrapolated data from other groups/research(Yogman et al., 2016). This makes it difficult to undertake research and prevents understanding of a family's needs so that services can be improved. Therefore, it is recommended that governments and paediatric healthcare services implement processes that enable the collection of data from the whole family. This could feasibly be implemented within a hospital or outpatient-based setting, considering that multiple data collection points are already embedded within healthcare systems. However, it would most likely need to occur system-wide, with data collected as part of the standard admission process and collated by health authorities. This would enable a better understanding of the composition of families and would ultimately improve the delivery of services to families by enabling services to be tailored to families' needs.

Given the research findings, a feasibility study is recommended to be undertaken to improve the delivery of services to pregnant mothers. It is suggested that the most efficient process for delivering this is via a partnership with health department maternity services, which have the expertise and resources to support pregnant mothers. Within the current health services in Western Australia, discussions have commenced with maternity services and government officials regarding implementing a pilot study that explores the most efficient way to deliver these services. Currently, there are community-based midwifery services that deliver care within the home. Translating these services to the oncology setting may be a low-cost method to support pregnant women. Importantly, it is also recommended that data is collected on the number of mothers who are pregnant when their children are diagnosed with cancer. This may be best collected within the hospital system (as pregnancy can occur during treatment) by allied health services (social workers/psychologists), and then reported to state-based maternity health services. This would enable an accurate assessment of the number of women who are pregnant when their child has cancer. It would also be beneficial to collect longitudinal data on the health and well-being of both mother and child. This would enable a more thorough understanding of the impact and appropriate support and healthcare to be provided. Again, this is most efficiently collected by a partnership with midwifery services. Alternatively, this data could be collected by childhood cancer institutes that could provide long-term funding within a research framework.

At a system wide level family-centred care (FCC) is a model of care which can potentially work to achieve improvements in support provided to family members of children with cancer. FCC acknowledges the critical role that family members play in the child’s life and the need to consider the relationships within the family when delivering care (Harrison, 2010; Mikkelsen & Frederiksen, 2011). While there has been a growing trend towards the FCC model, it can be difficult to implement and is therefore often inconsistent in its delivery so that needs of all families members are not considered (Cox, 2018; McEvoy & Creaner, 2022; Prchal & Landolt, 2012; Sheilds et al, 2010). While some of the principles of FCC, including involving family members in decision-making, have been incorporated, this often does not extend to the entire family and may be limited to parents (Harrison, 2010). Yogman and Garfield (2016) argue that paediatrics has been slow to adopt changes in the delivery of care and the adoption of the FCC. The original definition of FCC in the 1987 seminal work by the Association for the Care of Children's Health, amongst other aspects, emphasises the need to encourage and facilitate family support networks considering family member’s needs. It is therefore important that care delivered to families of children diagnosed with cancer consider the needs of all family members.

A further recommendation is that HCP are educated via hospital staff development services that the death of children from cancer within the healthcare setting impacts not only the immediate family of that child, but also has a ripple effect throughout the childhood cancer community. Childhood cancer mortality has improved significantly over the past 30 years, decreasing by 39% between 1998 and 2014 (CCQLD, 2017). However, a significant number of children still die, and childhood cancer remains the leading cause of death by disease for children (AIHW, 2019). Treatment for childhood cancer is often long and intense, with significant time spent in clinical settings. Families grow close, and thus, any death of a child impacts other families. It is recommended that a process be developed by allied health and medical teams that seeks to explore how grief counselling can be provided to families when needed. This may involve input from external organisations with expertise in grief management depending on services available with the health system. Previous research has shown that support services can be provided online (Hoey et al., 2008; Koumarianou et al., 2021; Moules et al., 2012). Thus, one potential opportunity for providing support would be developing an online grief support group run by allied health services within the hospital system or by external not for profit organisations. As with all services, these would need to be offered to suit the needs of the individual family member. For example, siblings have a distinct reaction to death because of their age and understanding. Grandparents experience grief dependent on their multiple roles in the family as both parents and grandparents. In addition, it may be of benefit to provide more education and support to HCP to assist them to manage the grief associated with the death of a child as currently there is limited support available to HCP thus limiting their ability to support families or manage their own well-being.

One common finding for individual family members in my study was the distress associated with witnessing painful procedures. While it is not possible to avoid the painful procedures that are vital to treating cancer, much can be done to reduce the distress that children experience and, thus, the distress for family members (Nabors et al., 2013). A range of practical and psychological techniques can be employed, including virtual reality technology and electronic games for IV access and other painful procedures (Birnie et al., 2018). Whilst many healthcare facilities have programs intended to mitigate paediatric procedural distress, these programs must be employed for all children early during treatment rather than as a reactionary measure after a child has already become traumatised (Birnie et al., 2018). Within the Australian system, this would have to be a whole-team approach involving allied health teams and clinical staff at all levels. Currently, the services are often delivered by allied health. However, these services are often only accessible sometime after diagnosis, and within the Australian health system, access to allied health can often be limited. While this equipment can be expensive, it reduces health costs by reducing staff time in managing child distress (Coyne et al., 2016). As this study has found importantly the benefits are not just for the child but for the whole family. By reducing the stress caused by witnessing stress it can be theorised that the long-term psychological distress may also be reduced.

At an individual level my research supports the current literature that families need to be provided with psychological support (Armstrong & Reaman, 2005; Aziza et al., 2019; Hoekstra-Weebers et al., 2012; Melguizo-Garín et al., 2023; Salvador et al., 2019). A systematic review of psychosocial supports found that they provide benefits and should be more widely available, but also noted that they often target mothers (Koumarianou et al., 2021). This research expands upon the existing knowledge to show that this support must be tailored to individual family members' needs. Specifically, it is recommended that this includes support provided to family members who acknowledge and recognise that societal norms impact how people will respond. For example, fathers need psychological support that acknowledges they receive societal messages that they need to be strong and not show emotion, so support needs to be delivered that is cognizant of these beliefs but also provides ways for them to manage the stress and anxiety (Yogman et al., 2016). In recent years, peer support groups have been introduced to support fathers, but these are not widespread, and often there is little structure or evaluation (Archibald et al., 2021; Campbell et al., 2004). Archibald et al. (2021) suggest that this support should include allowing fathers to do activities together rather than CBT talk therapy. Given this study's findings that fathers are reluctant to express emotions, activity-based support allows fathers to be with peers within their social system and discuss in a relaxed environment while normalising their emotions. Similarly, grandparents need to be provided with support that acknowledges their multifaceted roles in caring for multiple generations and the demands of having to alter numerous existing roles and adopt new ones. Younger siblings need to be provided with support that acknowledges their stage of development and that their understanding is shaped by their cognitive abilities. Thus, support provided to them needs to incorporate play and provides them with an opportunity to express their emotions.

Research has shown that family members with pre-existing medical conditions, social issues, or trauma often find it harder to adjust to the distress caused by childhood cancer (Koumarianou et al., 2021; Melguizo-Garín et al., 2023). Thus, support must be tailored to individual family members and adapted to suit the family member’s needs (Koumarianou et al., 2021). Koumarianou et al. (2021) found it is essential to have a systematic method to assess family members' needs for additional support. One possible method that could be utilised is a system similar to the Caring for Your Well-being tool developed by Massey University and the Child Cancer Foundation (Ross et al., 2019). This tool incorporates a booklet that thoroughly assesses various social, financial, spiritual, and health domains. This assessment is done by allied health staff at diagnosis and throughout the disease trajectory. This allows areas of need to be identified, for example, when mothers are pregnant. The Caring for Your Well-model being is funded by a private not for profit charity and this may be one method that could be utilised to implement assessment process. Given this current study’s finding that support needs to be tailored to the individual, this process would allow support to be implemented to meet all family members' needs. Furthermore, technological developments such as the use of tablet devices may facilitate the implementation of screening processes such as this.

Study limitations and future research

Although my study has enabled the development of a comprehensive understanding of the impact of childhood cancer on family members there are a number of limitations exist. Firstly, one of the limitations in my study reported in articles was that very few participants came from culturally and linguistically diverse backgrounds (CALD). This is a commonly reported problem with research that may reflect the complexities of recruiting families with limited English (Hughson et al., 2016; McDougall Jr et al., 2015). The Australian healthcare system does not keep statistics on parents' ethnicities, so it is difficult to assess what percentage of parents of children with cancer come from CALD families. Limited research funding precluded the use of interpreter services, which may have decreased access for participants whose native language is not English. People from CALD backgrounds may also have different attitudes to participation in research and a lack of awareness of the process may make them hesitant to participate (Hughson et al., 2016). Future studies should explore the specific experiences of CALD families. This also requires an understanding of how treatment impacts families. Childhood cancer treatment requires parents to understand complex treatments (Al Omari et al., 2021; Compas et al., 2015). Understanding and processing these treatments may incur more challenges for CALD families where English is not their first language (Watt et al., 2013). It may be more efficient for this research to be completed in a cooperative process with researchers from multiple organisations/hospitals across Australia to enable sufficient participant numbers and adequate funding to provide interpreters. Another potential limitation and area of future research is to explore the experiences of those who live in regional areas. While the sample did include a good representation of families who lived either regionally or outside the metropolitan area there was not scope within this study to specifically explore their experiences particularly in relation to challenges faced in being away from their home. It would be beneficial to have future research that specifically recruits families from regionally areas so that issues related to receiving treatment far from home can be explored. In addition, there was limited representation of participants from non-nuclear families. Attempts were made to recruit diverse families however often due to time constraints (for example sole parents) there was only limited representation. Upon discussion with stakeholders, it was suggested this may be because of the additional time constraints from juggling childcare in sole parent families might make it difficult take on any additional commitments. It may be useful to construct a study that specifically sets out to explore their experiences with the option of different interview structure (for example providing option to break interviews into short blocks) and emphasising the aim of the study to explore their unique experiences.

Another potential area of future study is to examine how childhood cancer is represented in the media and popular culture. Participants in my study frequently referenced popular culture, for example, Netflix movies, which framed their first responses to the child's cancer diagnosis. This often meant they interpreted the cancer diagnosis in the worst possible way and anticipated a negative outcome, which they had acquired from media representations, creating additional fear. Furthermore, these media portrayals are also likely to shape the perceptions and responses of the broader community and social network, thus compounding their impact. An exploration of this representation by various media forms would enable an understanding of people's perceptions, which would enable HCPs and groups that support families of children with cancer to address openly and explicitly some of these misconceptions and fears.

Childhood cancer treatment involves a range of healthcare professionals, including medical and radiation oncologists, surgeons, nursing staff, psychologists, occupational therapists, pathologists, dieticians, cardiologists, physiotherapists, and general practitioners. As reported by participants in my study, the treatment for childhood cancer is often distressing, requiring painful procedures and medications that make the children unwell and very distressed. Reports have demonstrated that handling complex and demanding healthcare delivery can lead to a risk of stress and burnout for HCPs (Enskär, 2012; Hecktman, 2012; Zander et al., 2013). Research in both adult and paediatric settings has shown that failure to manage the psychological aspects of healthcare professionals can negatively affect workplace performance and the ability of staff to communicate with families (Armuand et al., 2017; Hecktman, 2012; Mukherjee et al., 2014; Yates & Samuel, 2019). Despite the unique and specific issues involved in caring for children with cancer, including long disease trajectories and potential death of the child from cancer there is little known, how HCPs manage the impacts from observing the distress of both the child and the parents (Baenziger et al., 2020). Understanding the psychological impact on HCPs can help in two ways. First, understanding HCP's experiences provides the opportunity to provide appropriate evidence-based support including support to manage grief thus improving their psychological well-being. Second, supporting HCP's psychological well-being will enable healthcare professionals to provide more tailored support and care for families.

Conclusion

Childhood cancer is a challenging experience for all involved, profoundly altering not only the affected child but all those proximal to the child. While childhood cancer is a medical diagnosis requiring complex and intense treatment, it is also a diagnosis that requires thorough psychosocial care and management. Employing the ecological model, my research illustrates that the impact of cancer extends beyond the affected child to encompass the entire family. This study provides a cohesive analysis of the experiences of family members and explored how the different roles that people play in society impact how they experience childhood cancer understanding that people sit within a social context that influences their experiences and how they respond is essential. Support must acknowledge that people perform different functions within their families and the larger society and that the expectations created due to these roles can create additional stress.

While the trauma of childhood cancer cannot be prevented, and it will always be a painful and distressing experience, there is much that can be done to improve the supports that are provided to individual family members. Bronfenbrenner contended that relationships are bi-directional, with the family influencing the child and the child influencing the family (Bronfenbrenner, 1979). Thus, any improvements to the services for families will ultimately improve outcomes for children with cancer. Improving awareness within health services regarding individuals' societal roles and the conflicting expectations regarding behaviour and response to the diagnosis can enhance the delivery of suitable and effective treatments to families. This will ultimately improve both short and long-term outcomes for the child and their entire family.

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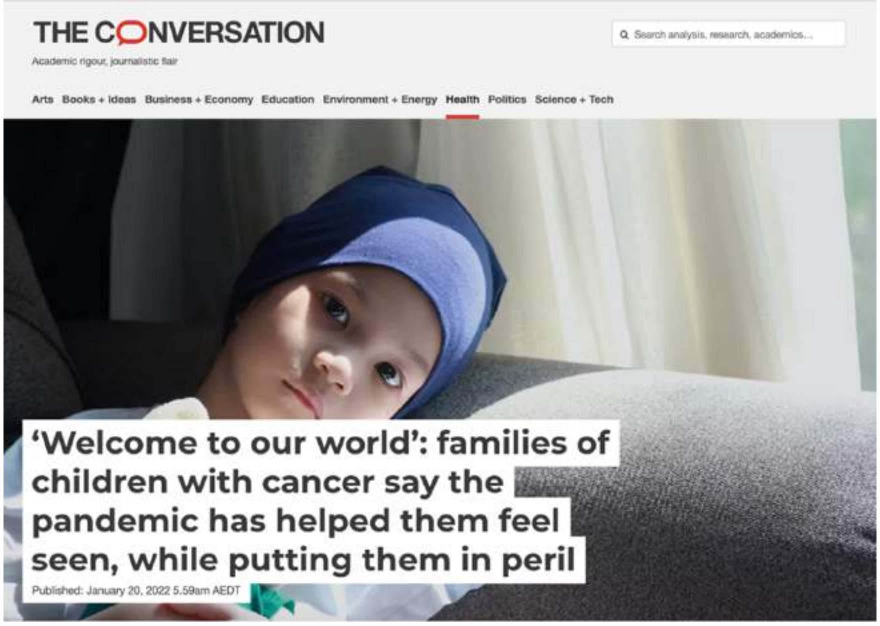
Appendices

Please note that for recruitment documents, there were multiple variations for different adult participants and between Australian states for most documents (with minor variations regarding location for interviews). Information sheets for adults also had different versions for different participants (mothers, fathers, and grandfathers). For simplicity, only one version has been included for all documents.

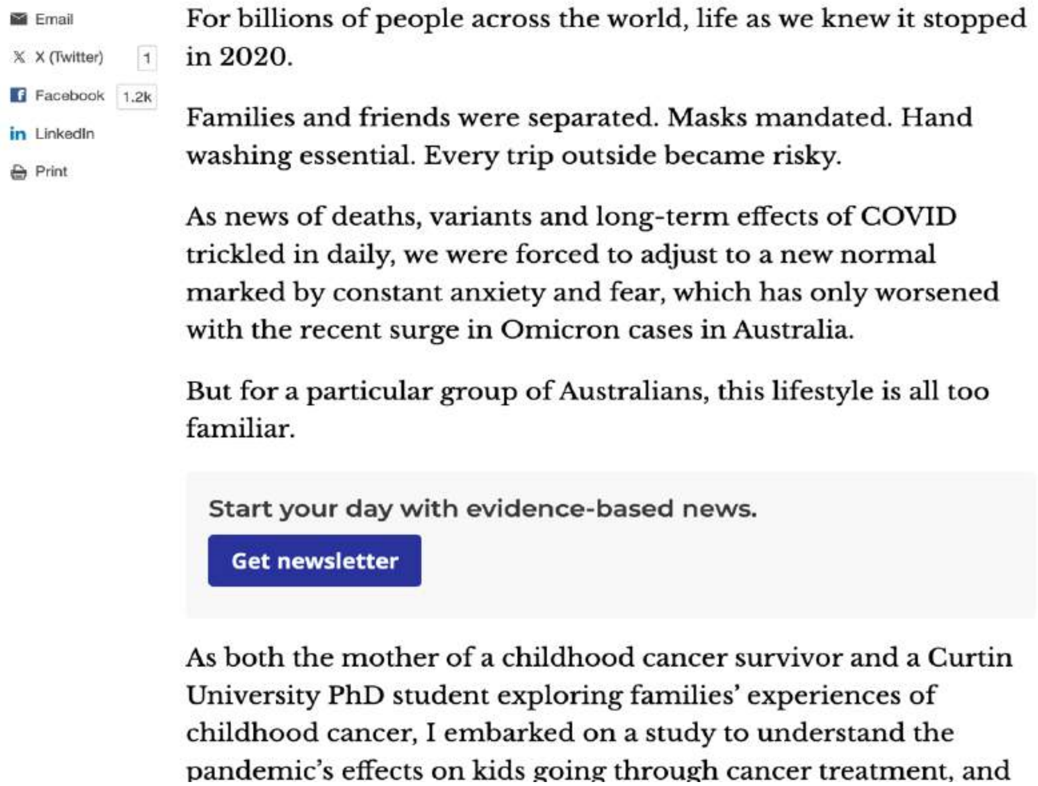
Appendix A: Media coverage

The Conversation - “Welcome to our world”: Families of children with cancer say pandemic has helped them feel seen, while putting them in peril. 20/01/22



‘Welcome to our world’: families of children with cancer say the pandemic has helped them feel seen, while putting them in peril

Published: January 20, 2022 5.59am AEDT



For billions of people across the world, life as we knew it stopped in 2020.

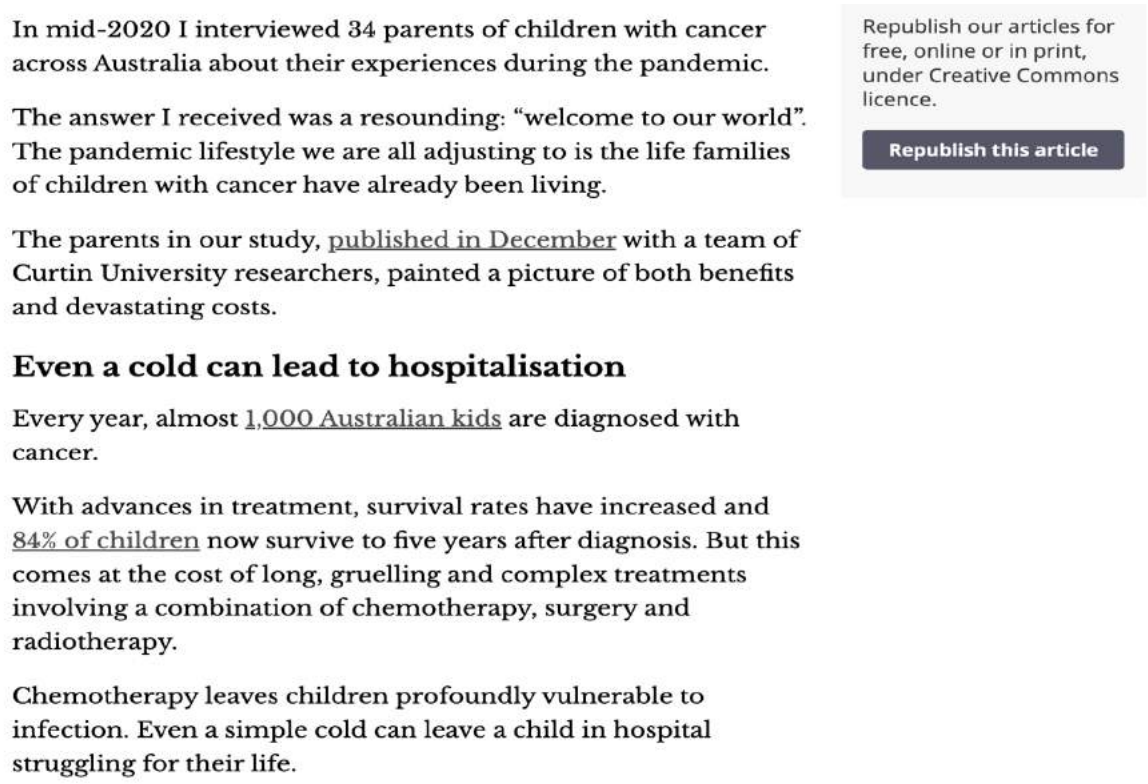
Families and friends were separated. Masks mandated. Hand washing essential. Every trip outside became risky.

As news of deaths, variants and long-term effects of COVID trickled in daily, we were forced to adjust to a new normal marked by constant anxiety and fear, which has only worsened with the recent surge in Omicron cases in Australia.

But for a particular group of Australians, this lifestyle is all too familiar.

Start your day with evidence-based news.

As both the mother of a childhood cancer survivor and a Curtin University PhD student exploring families’ experiences of childhood cancer, I embarked on a study to understand the pandemic’s effects on kids going through cancer treatment, and



In mid-2020 I interviewed 34 parents of children with cancer across Australia about their experiences during the pandemic.

The answer I received was a resounding: "welcome to our world". The pandemic lifestyle we are all adjusting to is the life families of children with cancer have already been living.

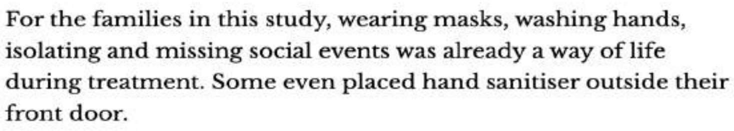
The parents in our study, published in December with a team of Curtin University researchers, painted a picture of both benefits and devastating costs.

Even a cold can lead to hospitalisation

Every year, almost 1,000 Australian kids are diagnosed with cancer.

With advances in treatment, survival rates have increased and 84% of children now survive to five years after diagnosis. But this comes at the cost of long, gruelling and complex treatments involving a combination of chemotherapy, surgery and radiotherapy.

Chemotherapy leaves children profoundly vulnerable to infection. Even a simple cold can leave a child in hospital struggling for their life.



For the families in this study, wearing masks, washing hands, isolating and missing social events was already a way of life during treatment. Some even placed hand sanitiser outside their front door.

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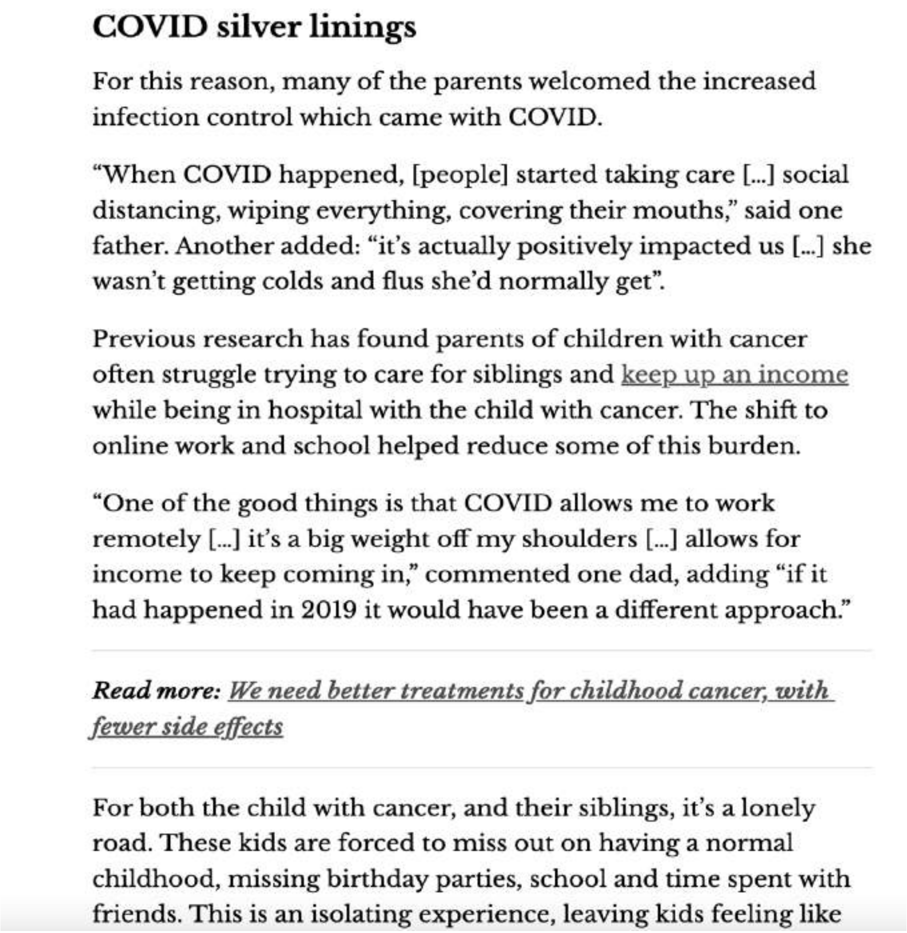
What does it mean to be immunocompromised? And why does this increas...
Some people's immune systems aren't able to stop foreign invaders, such as COVID-19, as well as the rest of the population. There are many reasons fo...

11:00 AM · Apr 15, 2020



COVID silver linings

For this reason, many of the parents welcomed the increased infection control which came with COVID.

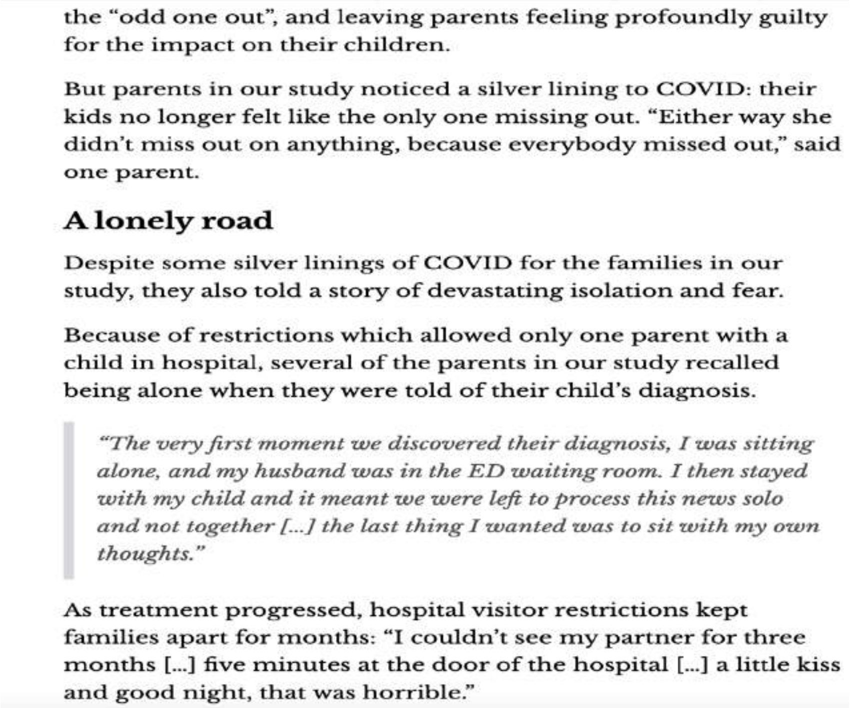
"When COVID happened, [people] started taking care [...] social distancing, wiping everything, covering their mouths," said one father. Another added: "it's actually positively impacted us [...] she wasn't getting colds and flus she'd normally get".

Previous research has found parents of children with cancer often struggle trying to care for siblings and keep up an income while being in hospital with the child with cancer. The shift to online work and school helped reduce some of this burden.

"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," commented one dad, adding "if it had happened in 2019 it would have been a different approach."

Read more: *We need better treatments for childhood cancer, with fewer side effects*

For both the child with cancer, and their siblings, it's a lonely road. These kids are forced to miss out on having a normal childhood, missing birthday parties, school and time spent with friends. This is an isolating experience, leaving kids feeling like the "odd one out", and leaving parents feeling profoundly guilty for the impact on their children.



But parents in our study noticed a silver lining to COVID: their kids no longer felt like the only one missing out. "Either way she didn't miss out on anything, because everybody missed out," said one parent.

A lonely road

Despite some silver linings of COVID for the families in our study, they also told a story of devastating isolation and fear.

Because of restrictions which allowed only one parent with a child in hospital, several of the parents in our study recalled being alone when they were told of their child's diagnosis.

> *"The very first moment we discovered their diagnosis, I was sitting alone, and my husband was in the ED waiting room. I then stayed with my child and it meant we were left to process this news solo and not together [...] the last thing I wanted was to sit with my own thoughts."*

As treatment progressed, hospital visitor restrictions kept families apart for months: "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."

COVID restrictions have made for a lonely pandemic for many parents of kids with cancer. Shutterstock

One mother described the gruelling experience as restrictions kept friends and family from visiting hospital: "For the whole year I was on my own [...] it was the loneliest year".

Travel restrictions also meant overseas parents and relatives couldn't visit to provide support. One parent said: "we definitely felt like we were in the trenches, just the three of us".

Read more: *Immunocompromised people make up nearly half of COVID-19 breakthrough hospitalizations – an extra vaccine dose may help*

Even though our study was conducted before the recent wave of Omicron cases, it can still teach us some valuable lessons going forward.

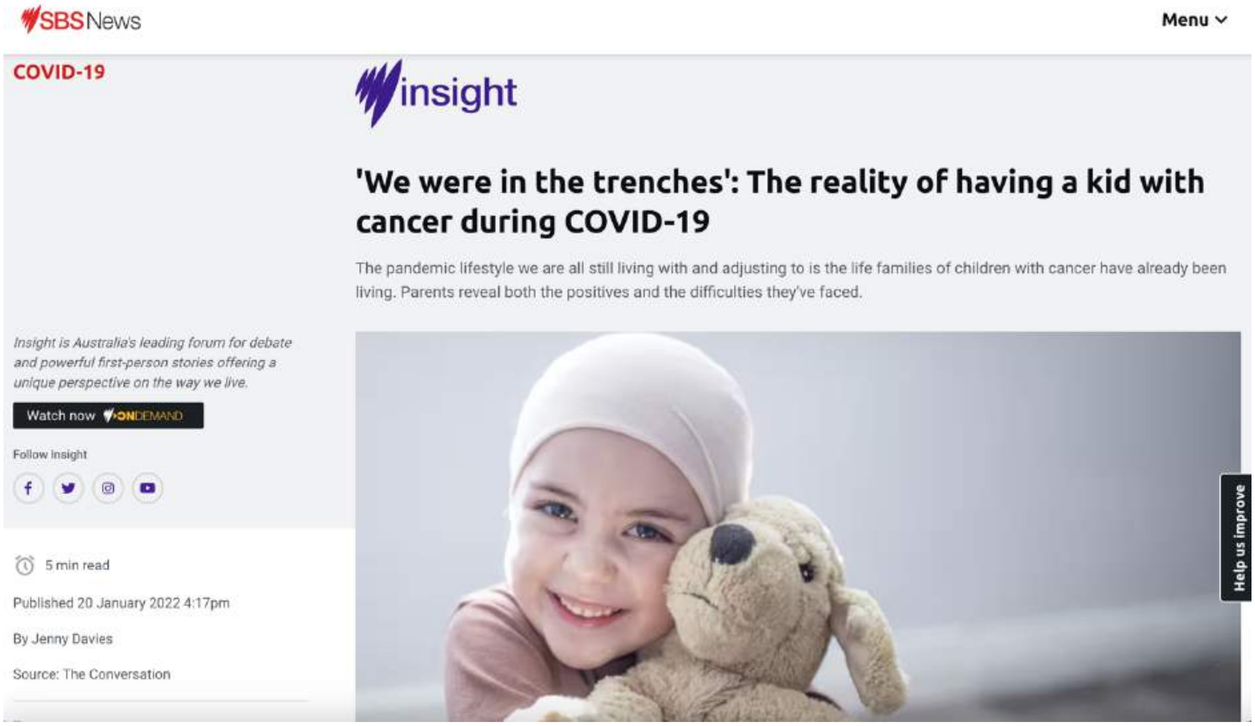
Despite the hardships of COVID, the virus has allowed us to develop new ways of connecting online, and increased flexibility for those unable to be there in person.

As we renegotiate what life with COVID looks like, we can use these lessons to protect and support the most vulnerable among us.

Cancer Coronavirus Childhood cancer Face masks COVID-19 Social distancing Hand sanitiser Immunocompromised

SBS NEWS - ‘We were in the trenches’: The reality of having a kid with cancer during COVID-19

20/01/22



'We were in the trenches': The reality of having a kid with cancer during COVID-19

The pandemic lifestyle we are all still living with and adjusting to is the life families of children with cancer have already been living. Parents reveal both the positives and the difficulties they've faced.

Insight is Australia's leading forum for debate and powerful first-person stories offering a unique perspective on the way we live.

5 min read

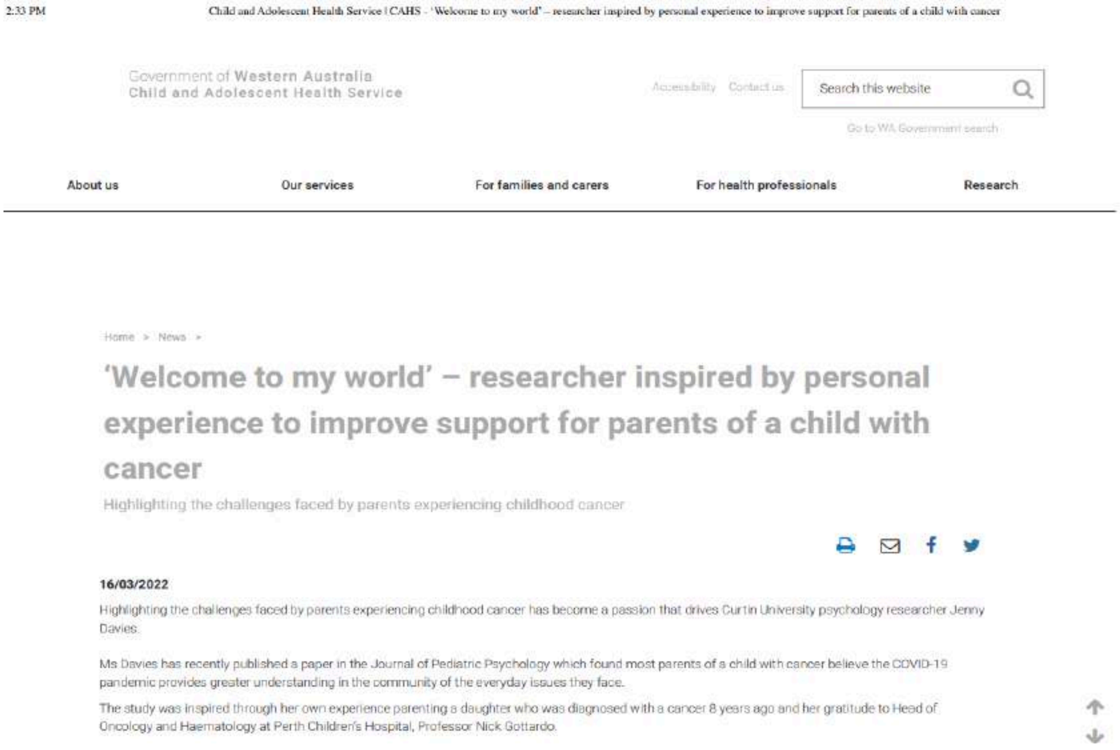
Published 20 January 2022 4:17pm

By Jenny Davies

Source: The Conversation

Child and Adolescent Services, Government of Western Australia – ‘Welcome to my World’ – researcher inspired by personal experience to improve support for parents of child with cancer.

16/03/22



2:33 PM Child and Adolescent Health Service | CAHS - 'Welcome to my world' – researcher inspired by personal experience to improve support for parents of a child with cancer

‘Welcome to my world’ – researcher inspired by personal experience to improve support for parents of a child with cancer

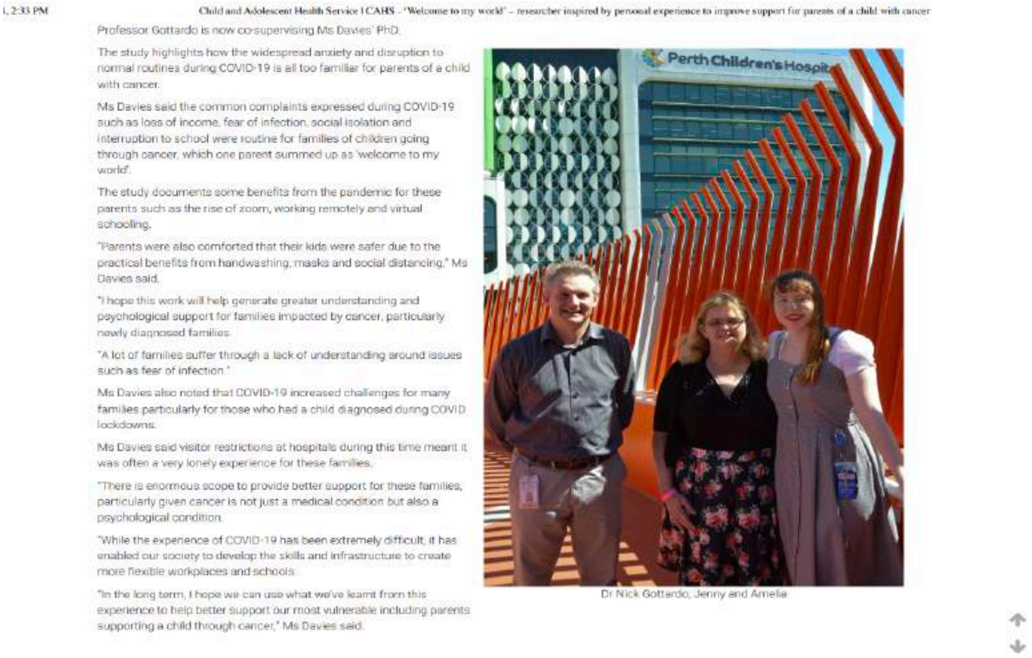
Highlighting the challenges faced by parents experiencing childhood cancer

16/03/2022

Highlighting the challenges faced by parents experiencing childhood cancer has become a passion that drives Curtin University psychology researcher Jenny Davies.

Ms Davies has recently published a paper in the Journal of Pediatric Psychology which found most parents of a child with cancer believe the COVID-19 pandemic provides greater understanding in the community of the everyday issues they face.

The study was inspired through her own experience parenting a daughter who was diagnosed with a cancer 8 years ago and her gratitude to Head of Oncology and Haematology at Perth Children's Hospital, Professor Nick Gottardo.



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Professor Gottardo is now co-supervising Ms Davies' PhD.

The study highlights how the widespread anxiety and disruption to normal routines during COVID-19 is all too familiar for parents of a child with cancer.

Ms Davies said the common complaints expressed during COVID-19 such as loss of income, fear of infection, social isolation and interruption to school were routine for families of children going through cancer, which one parent summed up as 'welcome to my world'.

The study documents some benefits from the pandemic for these parents such as the rise of zoom, working remotely and virtual schooling.

"Parents were also comforted that their kids were safer due to the practical benefits from handwashing, masks and social distancing," Ms Davies said.

"I hope this work will help generate greater understanding and psychological support for families impacted by cancer, particularly newly diagnosed families.

"A lot of families suffer through a lack of understanding around issues such as fear of infection."

Ms Davies also noted that COVID-19 increased challenges for many families particularly for those who had a child diagnosed during COVID lockdowns.

Ms Davies said visitor restrictions at hospitals during this time meant it was often a very lonely experience for these families.

"There is enormous scope to provide better support for these families, particularly given cancer is not just a medical condition but also a psychological condition.

"While the experience of COVID-19 has been extremely difficult, it has enabled our society to develop the skills and infrastructure to create more flexible workplaces and schools.

"In the long term, I hope we can use what we've learnt from this experience to help better support our most vulnerable including parents supporting a child through cancer," Ms Davies said.

Dr Nick Gottardo, Jenny and Amelia

The West Australian Today feature story – A Day in The Life

16/03/22

The West Australian

TODAY

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WEDNESDAY
March 16, 2022

A day in the life

How the pandemic has shone a light on the reality of everyday life for children with cancer

8 | TODAY | Wednesday, March 16, 2022

Wednesday, March 16, 2022 | TODAY Health | 9

Rare insight into a daily battle

The stresses, lockdowns and abandoned plans we've all struggled to cope with during the pandemic is a lifestyle children with cancer and their families know all too well

Katie Hampson

For many parents who have a child with cancer, when people complain about how the pandemic is disrupting their lives, the phrase that springs to mind is "welcome to our world".

In fact, Curtin University psychology researcher Jenny Davies says dealing with COVID-19 has shone a spotlight on the everyday issues and worries faced by these parents.

Ms Davies co-authored a paper recently published in the Journal of Pediatric Psychology revealing most parents of a child with cancer found the pandemic has helped others understand the complex challenges they have faced for so long.

"For example, most people did not care about infection control prior to the pandemic. Then, when COVID-19 hit, everyone felt vulnerable and adopted hygiene measures.

"The pandemic life we have all come to know is the life children with cancer live with all the time," Ms Davies notes.

"Parents with children undergoing chemotherapy already had hand sanitisers at their front door and would not let anyone into their home who is unwell and all of this was happening for them prior to the pandemic because it was necessary to protect their child."

Participants in the Australian-wide study, conducted in mid-2020, shared how disruptions to routines and anxiety about the future were already a part of their lives.

Many had grappled with loss of income, fear of infection, social isolation and interruption to school routines well before the pandemic hit.

"When your child is diagnosed with cancer, you are learning how to care for a child with a serious illness so your role in the world as a parent changes because the treatments make children very immune-suppressed to the point a common cold can hospitalise them," Ms Davies explains.

"When COVID happened, other people started taking more care and the parents in the study said they were comforted that their kids with cancer were safer due to the practical benefits from handwashing, masks and social distancing."

SILVER LININGS

While many of us have searched for the positives stemming from the pandemic, such as rediscovering nature and appreciating the simpler things in life, parents of children with cancer noticed other silver linings.

These included the rise in Zoom meetings, working remotely and online schooling.

"Children with cancer miss a lot of school and often their siblings have to miss attending school and catch-ups with friends because they risk bringing an infection home to the child in the family with cancer," Ms Davies explains.

"Online schooling has meant they are less likely to feel like 'the odd one out'."

Ms Davies says parents, too, often struggle to keep up an income while in hospital caring for their child and the shift to online work has helped with that.

Jenny Davies, right, and her daughter Amelia. Picture: ckson Flindell

A LONELY EXPERIENCE

On the flip side, the study revealed navigating a diagnosis and cancer treatments during the pandemic required a high level of fortitude from both the child with cancer and their family.

One participant shared the trauma of being alone when her child's diagnosis was delivered by a doctor; COVID rules at the time meant her husband had to remain outside.

Others described how lonely it felt when visitor restrictions were imposed at hospitals. Some parents reported being separated for months because pandemic rules prevented them from being together at their child's bedside.

Ms Davies says few studies to date have examined the impacts COVID-19 have had on children with cancer and their families.

She says her research found that despite the hardships the pandemic has brought, it has taught us some valuable lessons.

"The medical support for families in WA is brilliant but there needs to be more psychological, practical and community support," she says.

"I just hope we can use what we've learnt from the pandemic to help better support our most vulnerable."

Ms Davies revealed she was inspired to do the study because her daughter, Amelia, now 20, was diagnosed with a rare childhood cancer when she was 12.

She says she remembers what it's like to fear for your child's health.

She is also thankful to Professor Nick Gottardo, who is head of oncology and haematology at Perth Children's Hospital, because of the support he gave to their family throughout their ordeal.

Prof Gottardo is now co-supervising Ms Davies' PhD in the hope the findings will help other families get the support they need.

> "I just hope we can use what we've learnt from the pandemic to help better support our most vulnerable."

Picture: Kelsey Reid

Eglinton mum Janelle Preston's world was turned upside down when her son, Kade, now seven, was diagnosed with a rare brain cancer during the pandemic.

I took Kade to the emergency department at Perth Children's Hospital (PCH) last year because he had a headache and was vomiting.

I thought it was just a bad virus but PCH found a lesion on his brain.

Due to the pandemic restrictions, I was on my own when they told me he had brain cancer.

Our life changed, literally, in the blink of an eye.

Since Kade was diagnosed, my kids have been wearing masks to school. Things like a common cold mean nothing to most kids but it could kill Kade.

He just doesn't have any fight in his body. He needed a bone marrow transplant so his body has to build a brand new immune system which can take up to a year. This means my other children can't attend birthday parties or have friends over to play because they might bring germs into the house that can make Kade really sick.

I didn't see my husband and other children for 2½ months during Kade's most recent hospital stint because only one of us was allowed in due to restrictions.

If anything has been good about the pandemic, it is that people now have a better understanding of the life we live.

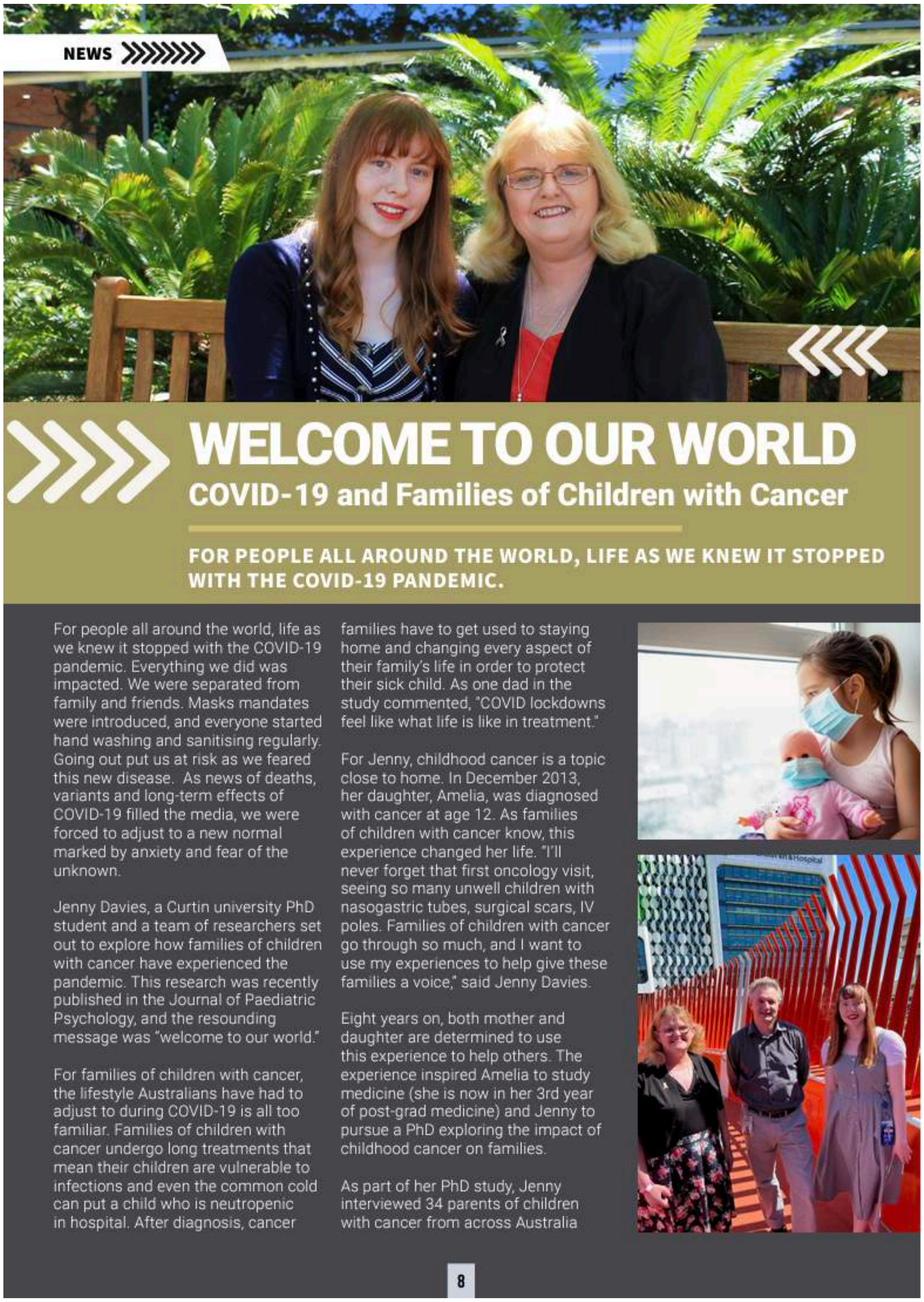
We live in fear about Kade's future and spend a lot of time isolating. This is the reality for families who have a child with cancer and there hasn't been much community awareness about this until now.

Sometimes when I am sitting in hospital with Kade, I think of things other people complain about like breaking up fights between their kids and I wish I was doing that normal stuff with Kade and his siblings.

Instead, my five-year-old comes out of school on a boiling hot day in her mask and when I tell her she can take it off for a bit — just while we walk to the car — she says "No, it's OK Mum. I don't want to pick up a germ that could hurt Kade."

Child Cancer Research Foundation newsletter cover story – Welcome to Our World: COVID-19 and Families of Children with Cancer

01/03/22



NEWS

WELCOME TO OUR WORLD

COVID-19 and Families of Children with Cancer

FOR PEOPLE ALL AROUND THE WORLD, LIFE AS WE KNEW IT STOPPED WITH THE COVID-19 PANDEMIC.

For people all around the world, life as we knew it stopped with the COVID-19 pandemic. Everything we did was impacted. We were separated from family and friends. Masks mandates were introduced, and everyone started hand washing and sanitising regularly. Going out put us at risk as we feared this new disease. As news of deaths, variants and long-term effects of COVID-19 filled the media, we were forced to adjust to a new normal marked by anxiety and fear of the unknown.

Jenny Davies, a Curtin university PhD student and a team of researchers set out to explore how families of children with cancer have experienced the pandemic. This research was recently published in the Journal of Paediatric Psychology, and the resounding message was "welcome to our world."

For families of children with cancer, the lifestyle Australians have had to adjust to during COVID-19 is all too familiar. Families of children with cancer undergo long treatments that mean their children are vulnerable to infections and even the common cold can put a child who is neutropenic in hospital. After diagnosis, cancer families have to get used to staying home and changing every aspect of their family's life in order to protect their sick child. As one dad in the study commented, "COVID lockdowns feel like what life is like in treatment."

For Jenny, childhood cancer is a topic close to home. In December 2013, her daughter, Amelia, was diagnosed with cancer at age 12. As families of children with cancer know, this experience changed her life. "I'll never forget that first oncology visit, seeing so many unwell children with nasogastric tubes, surgical scars, IV poles. Families of children with cancer go through so much, and I want to use my experiences to help give these families a voice," said Jenny Davies.

Eight years on, both mother and daughter are determined to use this experience to help others. The experience inspired Amelia to study medicine (she is now in her 3rd year of post-grad medicine) and Jenny to pursue a PhD exploring the impact of childhood cancer on families.

As part of her PhD study, Jenny interviewed 34 parents of children with cancer from across Australia about their experiences of the COVID-19 pandemic.

This research paints a complex landscape of navigating the pandemic in the midst of childhood cancer treatment.

Increased awareness in the community about infection control measures helped protect children with cancer. "When COVID happened, [people] started taking care… social distancing, wiping everything, covering their mouths," said one father, with another adding "it's actually positively impacted us, she wasn't getting colds and flus she'd normally get."

Jenny found that participants found that staying home during lockdowns 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 sniffle…and having to say 'Sorry, you cannot come in'…we did not have to have any difficult conversations."

> **"For families of children with cancer, the lifestyle Australians have had to adjust to during COVID-19 is all too familiar."**

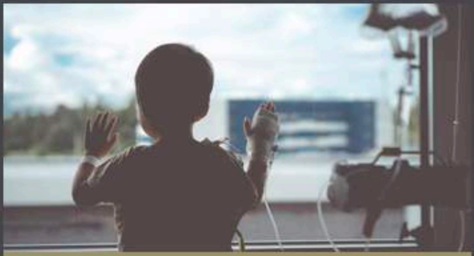
Fear of infection also means missing out on school, birthday parties and social gatherings, for both the child with cancer and their siblings. This is an isolating experience, leaving kids feeling like "the odd one out" and parents feeling guilty.

An unexpected outcome of the pandemic was that immunocompromised kids no longer felt they were the only ones missing out, as we all were forced to find new ways to connect through social isolation.

"Through previous research we've done, we've often heard that parents of children with cancer feel torn trying to care for their sick child whilst also keeping up an income and caring for the siblings. It can feel like an impossible choice," said Jenny.

The COVID-19 pandemic helped alleviate some of these pressures through the shift to online work and schooling.

As one of the participants in her study noted, "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" adding "if this had happened in 2019 it would have been a different approach."



A LONELY EXPERIENCE

But despite the silver linings of the COVID-19 experience for families of children with cancer, there were devastating consequences.

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."

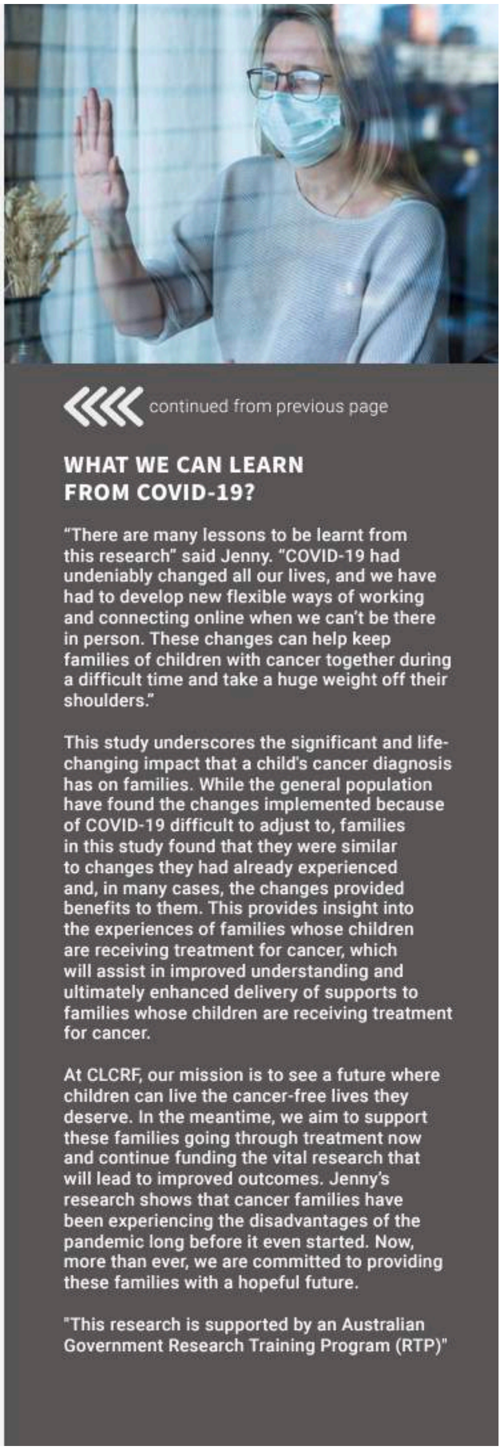
Participants also reflected that being away from siblings was difficult. "My little one…I couldn't help him with his online learning… They had to fend for themselves … The guilt … I can't begin to tell you," one mother described. This loneliness was particularly pronounced for those who received a diagnosis during the tight lockdown rules.

As reflected in one mother's reflection "The very first moment we discovered their diagnosis, I was sitting alone, and my husband was in the ED waiting room. I then stayed with my child and it meant we were left to process this news solo and not together… the last thing I wanted was to sit with my own thoughts" recalled one mother.

Participants in Jenny's study 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. 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."

COVID-19 travel restrictions also prevented overseas family from visiting and providing support which families indicated made it an isolating experience. Another negative of COVID-19 was that many of the hospital-based supports that are so very important had to stop as one parent described "a lot of the stuff that I think they do to keep the kids' spirits up…All that stopped completely. Making a difficult situation far worse.

story continued overleaf…



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WHAT WE CAN LEARN FROM COVID-19?

"There are many lessons to be learnt from this research" said Jenny. "COVID-19 had undeniably changed all our lives, and we have had to develop new flexible ways of working and connecting online when we can't be there in person. These changes can help keep families of children with cancer together during a difficult time and take a huge weight off their shoulders."

This study underscores the significant and life-changing impact that a child's cancer diagnosis has on families. While the general population have found the changes implemented because of COVID-19 difficult to adjust to, families in this study found that they were similar to changes they had already experienced and, in many cases, the changes provided benefits to them. 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 whose children are receiving treatment for cancer.

At CLCRF, our mission is to see a future where children can live the cancer-free lives they deserve. In the meantime, we aim to support these families going through treatment now and continue funding the vital research that will lead to improved outcomes. Jenny's research shows that cancer families have been experiencing the disadvantages of the pandemic long before it even started. Now, more than ever, we are committed to providing these families with a hopeful future.

"This research is supported by an Australian Government Research Training Program (RTP)"

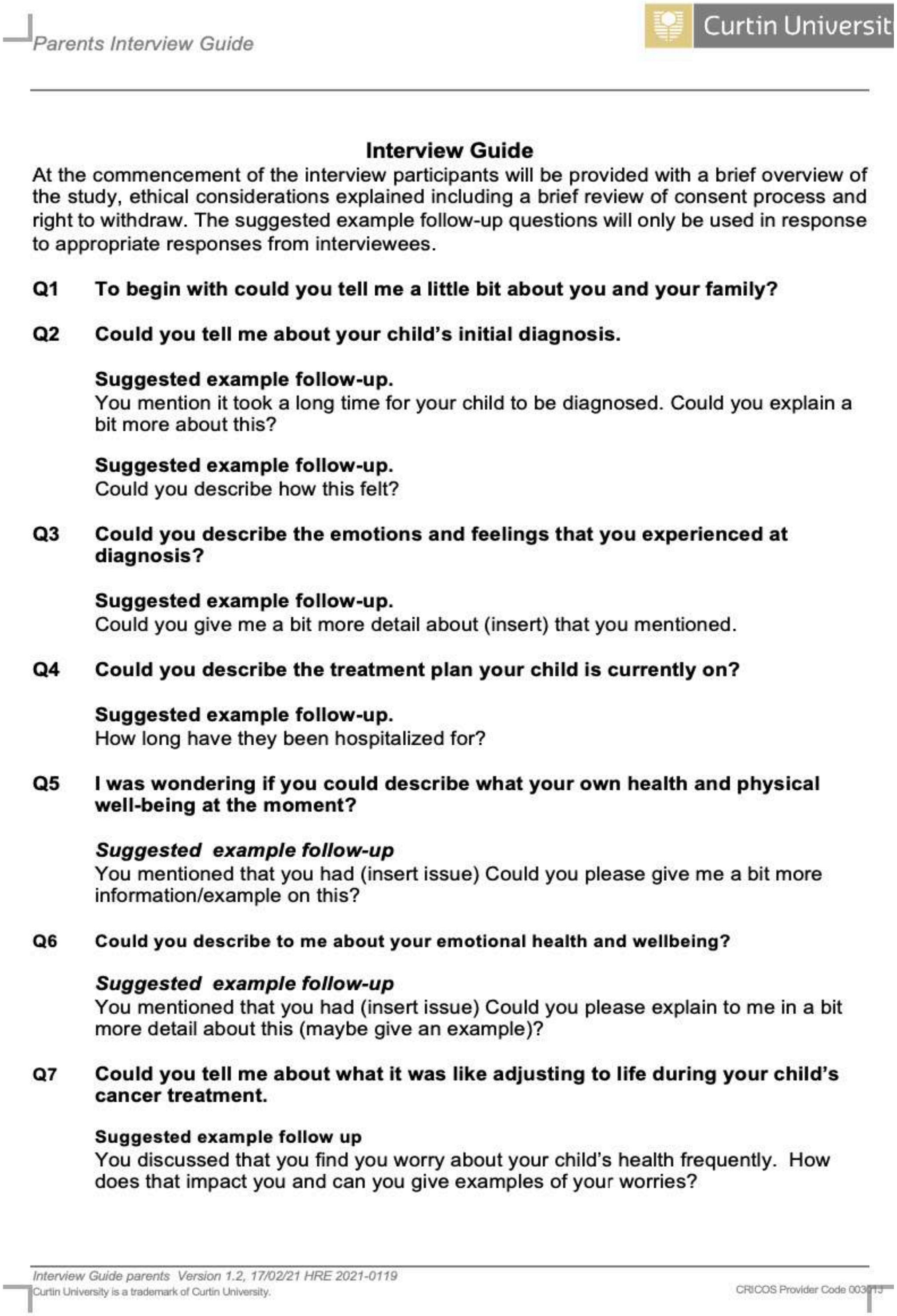
Appendix B: Sample demographics of studies reporting on parents/carers

Author	Year	Mothers %	Fathers %	Method	Study focus
Al-Gamal et al.	2019	72 % (82)	17.3% (18)	Qualitative	Health Satisfaction
Ångström-Brännström et al.	2010	89% (8)	11% (1)	Qualitative	Parental perception of what comforts a child
Azizia et al.	2019	73% (73)	27% (27)	Quantitative	Psychological distress
Baenziger et al.	2020	90% (52)	10% (6)	Qualitative	Parents communication experiences
Bally et al.	2014	75% (12)	25% (4)	Qualitative	Understanding parental experiences
Barakat et al.	2021	90% (301)	9.3% (31)	Quantitative	Predictors of caregiver's resilience
Klassen et al.	2008	88% (388)	11.4% (50)	Quantitative	Impact of caring on parents' Health QOL
Koohkan et al.	2019	74% (26)	25.8% (8)	Qualitative	Health information needs of parents
Koyu & Arslan	2021	98% (169)	1.7% (3)	Quantitative	Physical & psychosocial effects
Lewandowska et al.	2021	85% (680)	15% (120)	Mixed methods	Impact of child's cancer on parents
McLoone et al.	2013	75% (39)	25% (13)	Quantitative	Parental sleep
Melguizo-Garín et al.	2023	66% (74)	33.9% (38)	Quantitative	Importance of social support for parents
Meltzer et al.	2012	89% (52)	11% (7)	Quantitative	Parental sleep
Okado et al.	2014	83%	12.2%	Quantitative	Association between parent and child distress
Rensen et al.	2022	78% (94)	21.7% (26)	Quantitative	Parental sleep during treatment
Average %		81%	19%		

**Please note that this table is not exhaustive but is a sample of study demographics*

Appendix C: Interview guides

Parents' Interview guide



Parents Interview Guide

Curtin Universit

Interview Guide

At the commencement of the interview participants will be provided with a brief overview of the study, ethical considerations explained including a brief review of consent process and right to withdraw. The suggested example follow-up questions will only be used in response to appropriate responses from interviewees.

Q1 To begin with could you tell me a little bit about you and your family?

Q2 Could you tell me about your child's initial diagnosis.

Suggested example follow-up.
You mention it took a long time for your child to be diagnosed. Could you explain a bit more about this?

Suggested example follow-up.
Could you describe how this felt?

Q3 Could you describe the emotions and feelings that you experienced at diagnosis?

Suggested example follow-up.
Could you give me a bit more detail about (insert) that you mentioned.

Q4 Could you describe the treatment plan your child is currently on?

Suggested example follow-up.
How long have they been hospitalized for?

Q5 I was wondering if you could describe what your own health and physical well-being at the moment?

Suggested example follow-up
You mentioned that you had (insert issue) Could you please give me a bit more information/example on this?

Q6 Could you describe to me about your emotional health and wellbeing?

Suggested example follow-up
You mentioned that you had (insert issue) Could you please explain to me in a bit more detail about this (maybe give an example)?

Q7 Could you tell me about what it was like adjusting to life during your child's cancer treatment.

Suggested example follow up
You discussed that you find you worry about your child's health frequently. How does that impact you and can you give examples of your worries?

Interview Guide parents Version 1.2, 17/02/21 HRE 2021-0119
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Q8 Could you describe to me a typical day during your child's cancer treatment?

Suggested example follow-up
You mentioned many low days, could you perhaps give me an example of one of the hardest days

You highlighted also moments of laughter could you tell me an example of one these?

Q9 Has your child's cancer diagnosis impacted your family roles and responsibilities?

Suggested example follow-up
Could you describe how as it changed the routines in the family?
How has it changed family activities/get togethers?
What is one of the major changes?
What's it like adjusting to these?

Q10 Has your work been altered by your child's cancer diagnosis
Suggested example follow-up
You mentioned your boss do you feel they are supportive/accommodation hours etc while your child is sick?
How have family finances been impacted by this experience?

Support

Q11 What challenges have you faced during your child's treatment?

Suggested example follow-up
You discussed (practical challenge) could you explain to me about this challenge?
How have these challenges impacted you emotionally?
What are the social impacts of these factors?

Q12 During your child's cancer treatment what sources of support have been available to you?

Suggested example follow-up
How much did you make use of the offered support?

Suggested example follow up
You mentioned lack of support for siblings/family. Could you explain a bit more about this?

Suggested example follow up
You mentioned support came from various places can you give examples
Can you talk about the support you have received from family?
Can you talk about the support you have received from community?
Can you talk about the support you have received from workplace?

Q13 Could you describe to me what supports you would have found most helpful?

Suggested example follow-up
What sort of social support what you find helpful?
You talked about the hospital services what sort of hospital support would you find helpful?

Q14 How do you think the wider community perceives childhood cancer?

Suggested example follow-up
You mentioned friends don't understand. Could you explain a bit more about this?
In your answer you described people in your community don't understand could you describe a bit more about this and maybe give an example of the comments you referred to?

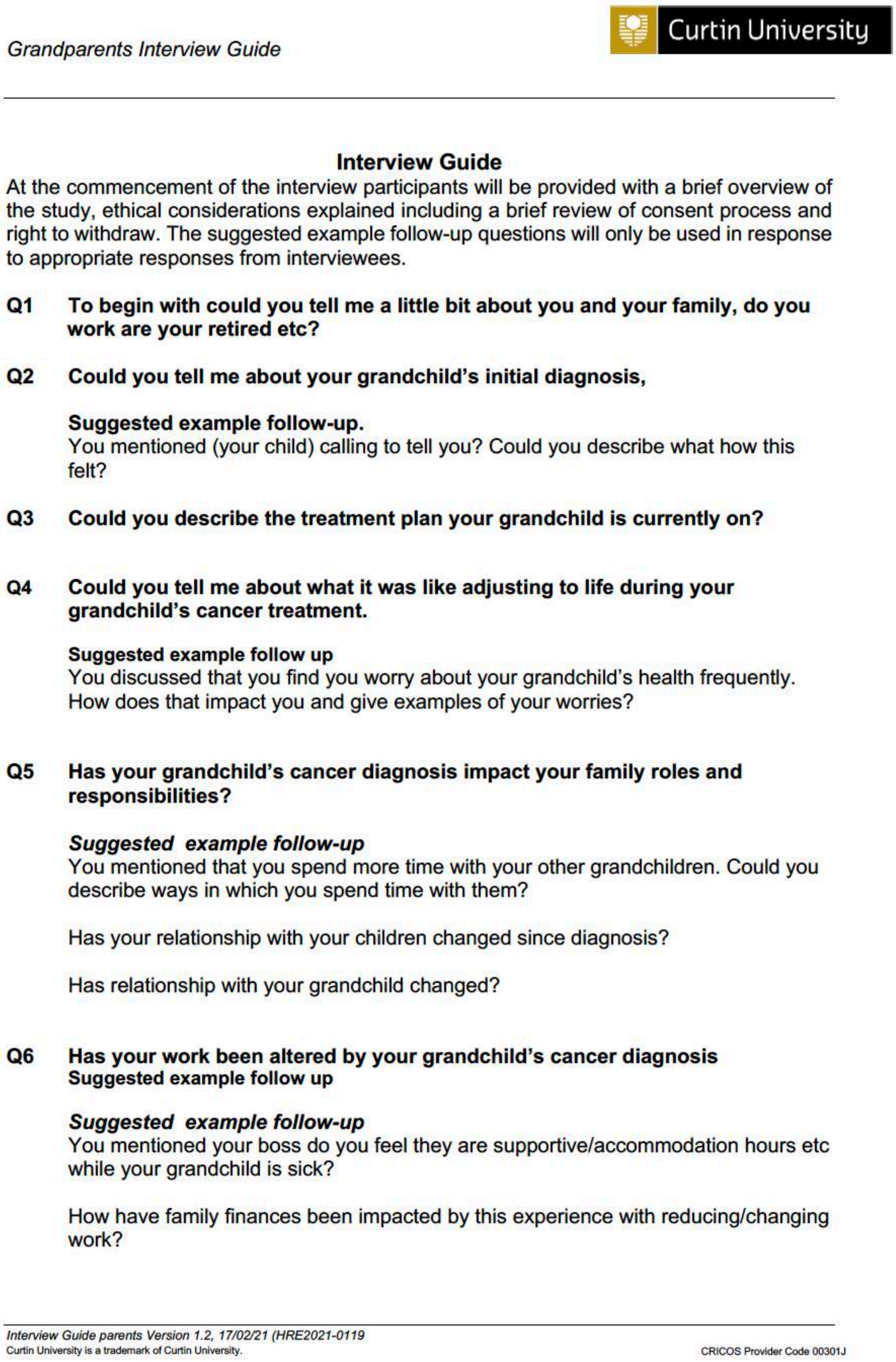
What impacts have these expectations of the wider community had on you and your family?

What were your perceptions of childhood cancer prior to diagnosis and the level of support they received?

Q15 What advice would give to parents whose child has just been diagnosed with cancer that you wish you had known when your child started treatment?

Q16 Is there anything else you would like to share?

Grandparents' Interview guide



Grandparents Interview Guide

Curtin University

Interview Guide

At the commencement of the interview participants will be provided with a brief overview of the study, ethical considerations explained including a brief review of consent process and right to withdraw. The suggested example follow-up questions will only be used in response to appropriate responses from interviewees.

Q1 To begin with could you tell me a little bit about you and your family, do you work are your retired etc?

Q2 Could you tell me about your grandchild's initial diagnosis,

Suggested example follow-up.
You mentioned (your child) calling to tell you? Could you describe what how this felt?

Q3 Could you describe the treatment plan your grandchild is currently on?

Q4 Could you tell me about what it was like adjusting to life during your grandchild's cancer treatment.

Suggested example follow up
You discussed that you find you worry about your grandchild's health frequently. How does that impact you and give examples of your worries?

Q5 Has your grandchild's cancer diagnosis impact your family roles and responsibilities?

Suggested example follow-up
You mentioned that you spend more time with your other grandchildren. Could you describe ways in which you spend time with them?

Has your relationship with your children changed since diagnosis?

Has relationship with your grandchild changed?

Q6 Has your work been altered by your grandchild's cancer diagnosis
Suggested example follow up

Suggested example follow-up
You mentioned your boss do you feel they are supportive/accommodation hours etc while your grandchild is sick?

How have family finances been impacted by this experience with reducing/changing work?

Interview Guide parents Version 1.2, 17/02/21 (HRE2021-0119

Q7 I was wondering if you could describe what your own health and emotional well-being?

Suggested example follow-up
You mentioned that you had (insert issue) Could you please explain to me in a bit more detail about this maybe give an example?

Support

Q8 What challenges have you faced during your grandchild's treatment?

Q9 What were your opinions on childhood cancer prior to your grandchild's cancer diagnosis and the level of support provided to families.

Q10 During your grandchild's cancer treatment what sources of support have been available to you?

Q11 Could you describe to me what supports you would have found most helpful?

Suggested example follow-up
What sort of social support what you find helpful?
You talked about the hospital services what sort of hospital support would you find helpful?

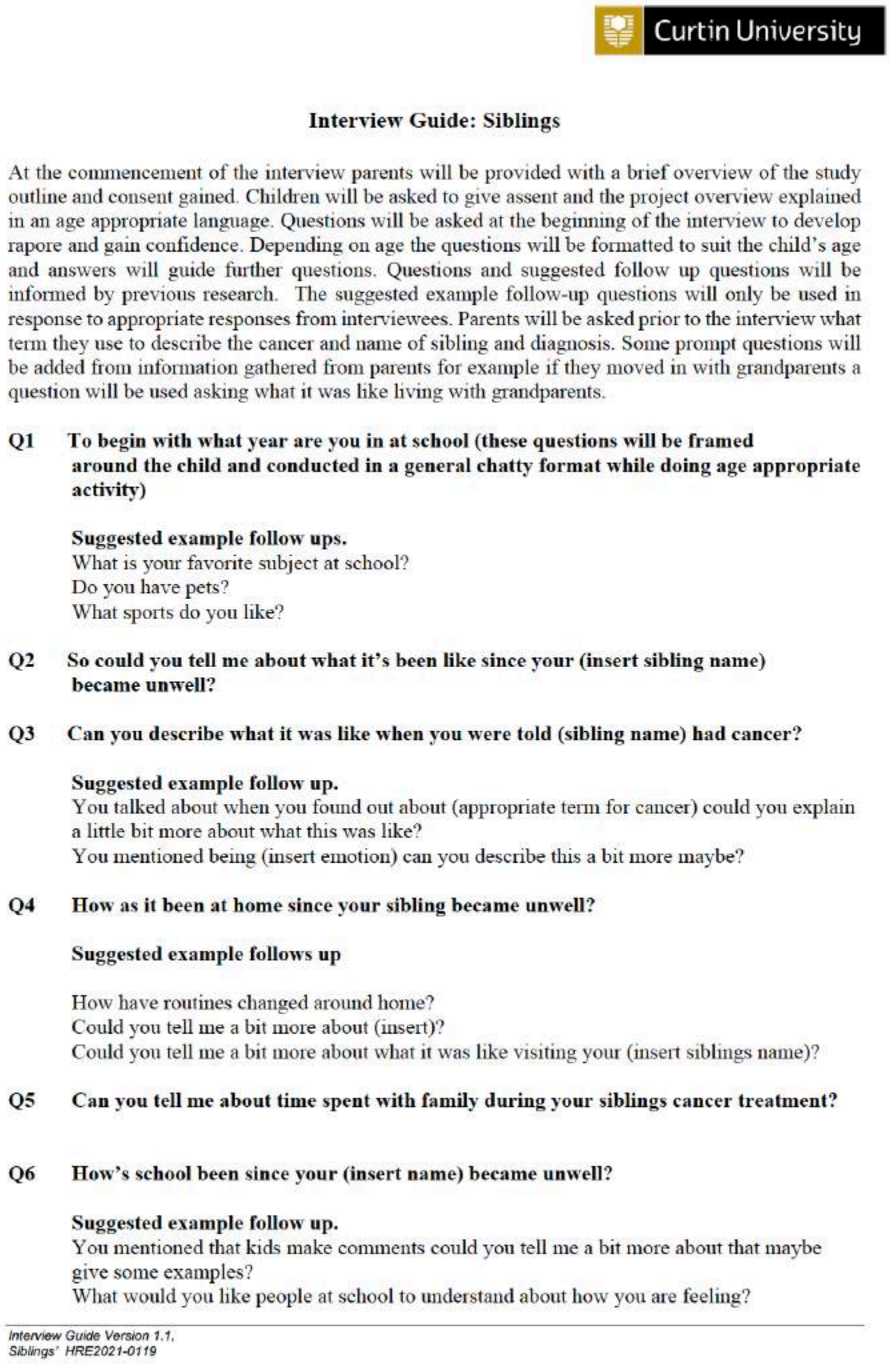
Q12 How do you think the wider community perceives childhood cancer?

Suggested example follow-up
You mentioned friends don't understand. Could you explain a bit more about this?
In your answer you described people in your community don't understand could you describe a bit more about this and maybe give an example of the comments you referred to?

What impacts have these expectations of the wider community had on you and your family?

Q13 Is there anything else you would like to share

Siblings' interview guide



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Interview Guide: Siblings

At the commencement of the interview parents will be provided with a brief overview of the study outline and consent gained. Children will be asked to give assent and the project overview explained in an age appropriate language. Questions will be asked at the beginning of the interview to develop rapore and gain confidence. Depending on age the questions will be formatted to suit the child's age and answers will guide further questions. Questions and suggested follow up questions will be informed by previous research. The suggested example follow-up questions will only be used in response to appropriate responses from interviewees. Parents will be asked prior to the interview what term they use to describe the cancer and name of sibling and diagnosis. Some prompt questions will be added from information gathered from parents for example if they moved in with grandparents a question will be used asking what it was like living with grandparents.

Q1 To begin with what year are you in at school (these questions will be framed around the child and conducted in a general chatty format while doing age appropriate activity)

Suggested example follow ups.
What is your favorite subject at school?
Do you have pets?
What sports do you like?

Q2 So could you tell me about what it's been like since your (insert sibling name) became unwell?

Q3 Can you describe what it was like when you were told (sibling name) had cancer?

Suggested example follow up.
You talked about when you found out about (appropriate term for cancer) could you explain a little bit more about what this was like?
You mentioned being (insert emotion) can you describe this a bit more maybe?

Q4 How as it been at home since your sibling became unwell?

Suggested example follows up

How have routines changed around home?
Could you tell me a bit more about (insert)?
Could you tell me a bit more about what it was like visiting your (insert siblings name)?

Q5 Can you tell me about time spent with family during your siblings cancer treatment?

Q6 How's school been since your (insert name) became unwell?

Suggested example follow up.
You mentioned that kids make comments could you tell me a bit more about that maybe give some examples?
What would you like people at school to understand about how you are feeling?

Interview Guide Version 1.1,
Siblings' HRE2021-0119

What would you like school to do make it easier for you?

Q7 **If you had met someone with a brother/sister who had cancer what would you tell them?**

Q8 **Is there anything else you would like to share.**

Appendix D: COREQ checklist

COREQ checklist **Domain 1: Research team and reflexivity**		
Personal Characteristics		
1.	**Interviewer/facilitator**	**Which author/s conducted the interview or focus group?** *Jenny Davies: PhD student*
2.	**Credentials**	**What were the researcher's credentials?** ***E.g., PhD, MD*** BA (Hons), Post Grad Dip (Public Policy), BA Psychology (Hons) *PhD candidate*
3.	**Occupation**	**What was their occupation at the time of the study?** *PhD candidate and research officer*
4.	**Gender**	**Was the researcher male or female?** *Female*
5.	**Experience and training**	**What experience or training did the researcher have?** *4 years training psychology honours. 15 years' experience in health care*
Relationship with participants		
6.	**Relationship established**	**Was a relationship established prior to study commencement?**

		Participants were not known to researcher personally prior to the study.
7.	**Participant knowledge of the interviewer**	**What did the participants know about the researcher? *e.g., personal goals, reasons for doing the research?*** *Participants were provided with information sheet which outlined reason for research (to improve services to childhood cancer families.) Participants who were recruited via social media were not aware of researchers inside status prior to volunteering. Some participants who were recruited by word of mouth were aware of the researcher's insider status prior to volunteering. The researcher discussed with most adult participants her insider status during the interview.*
8.	**Interviewer characteristics**	**What characteristics were reported about the interviewer/facilitator? e.g., *Bias, assumptions, reasons, and interests in the research topic?*** *Insider researcher status was declared in manuscripts where possible depending on reviewer feedback.*
Domain 2: study design		
Theoretical framework		
9.	**Methodological orientation and Theory**	**What methodological orientation was stated to underpin the study? *e.g., grounded theory, discourse analysis, ethnography, phenomenology, content analysis?*** *This study methodological orientation was phenomenology with a constructivism framework using qualitative design.*
Participant selection		

10.	**Sampling**	**How were participants selected? *e.g., purpose, convenience, consecutive, snowball?*** *Purposive and snowballing.*
11.	**Method of approach**	**How were participants approached? e*.g., face-to-face, telephone, mail, email?*** *Participants were recruited via social media (Facebook) and flyers. Initial contact was made mostly by email with 4 by phone.*
12.	**Sample size**	**How many participants were in the study?** *77*
13.	**Non-participation**	**How many people refused to participate or dropped out? Reasons?** *4 withdrew due to family illness (because of COVID which mean they were busy). One child changed their mind about participation. 5 parents did not follow up after initial contact. 2 grandparents did not follow up after initial contact. 5 adults expressed but did not meet eligibility criteria.*
Setting		
14.	**Setting of data collection**	**Where was the data collected? e*.g., home, clinic, workplace?*** *Majority were conducted online.* *11 adults' interviews conducted at home.* *12 adults' interviews conducted at Childhood Cancer organisation family room.* *4 conducted at adults' workplace meeting room.*

		1 sibling interview conducted at home.
15.	**Presence of non-participants**	**Was anyone else present besides the participants and researchers?** *Participants were interviewed on their own. Three mothers had infant/toddlers' children with them.*
16.	**Description of sample**	**What are the important characteristics of the sample?** ***e.g., demographic data, date?*** 21 fathers aged 33 -51 years (*M* = 41 years, *SD* = 5). 23 mothers aged 29-50 years (M=36 years, SD = 4.2). 20 grandparents (13 grandmothers and 7 grandfathers) aged from 41-77 years (M= 65 years, SD=9). 13 siblings (7 boys and 6 girls) aged between 8-12 years (*M* = 9.8, *SD* = 1.6)
Data collection		
17.	**Interview guide**	**Were questions, prompts, guides provided by the authors? Was it pilot tested?** *Interview guides were developed by PhD candidate based on research. Input was given by consumer representatives, research team and ethics committee. Final interview guides were reviewed by consumer representatives.*
18.	**Repeat interviews**	**Were repeat interviews carried out? If yes, how many?** *No.*

19.	**Audio/visual recording**	**Did the research use audio or visual recording to collect the data?** *Interviews were digitally audio recorded*
20.	**Field notes**	**Were field notes made during and/or after the interview or focus group?** *Researcher recorded initial observations and thoughts following each interview.*
21.	**Duration**	**What was the duration of the interviews or focus group?** *Length of interviews from 15 to 150 minutes*
22.	**Data saturation**	**Was data saturation discussed?** *Data saturation was discussed for each manuscript.*
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction? *Transcripts were not returned to participants,*
Domain 3: analysis and findings		
Data analysis		
24.	**Number of data coders**	**How many data coders coded the data?** *5*
25.	**Description of the coding tree**	**Did authors provide a description of the coding tree?** *No*

26.	**Derivation of themes**	**Were themes identified in advance or derived from the data?** *Themes were derived from the data.*
27.	**Software**	**What software, if applicable, was used to manage the data?** *No software was used.*
28.	**Participant checking**	**Did participants provide feedback on the findings?** *After initial analysis l themes were returned to a random selection or participants for feedback.*
Reporting		
29.	**Quotations presented**	**Were participant quotations presented to illustrate the themes / findings?** Quotations were provided to illustrate themes
30.	**Data and findings consistent**	**Was there consistency between the data presented and the findings?** *Yes*
31.	**Clarity of major themes**	**Were major themes clearly presented in the findings?** *Yes*
32.	**Clarity of minor themes**	**Is there a description of diverse cases or discussion of minor themes?** *Yes*

Appendix E: Ethics approval letter

Ethics removed for publication

Appendix F: Recruitment flyers

Adults' recruitment flyers

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PARTICIPANTS NEEDED
MOTHERS OF CHILDREN WHO HAVE BEEN DIAGNOSED WITH CANCER

I'm currently enrolled a PhD psychology degree at Curtin University. My research project is exploring mothers' experiences when their child is diagnosed with cancer. I'm asking mothers to volunteer to be interviewed to gain an understanding of their experiences

WHAT WILL IT INVOLVE?

- **All interviews will take approximately 60 mins**
- **Interviews will be completed either via tele-conference, at the Kids Cancer Support Group drop in centre, or at a venue of your choosing including your home**

WHAT ARE THE ELIGIBILITY CRITERIA?

- **Your child must be currently receiving or completed treatment within previous 15 months**
- **Your child must be 17 years or younger during treatment**
- **For the purposes of this study any adult in parental role or caregiving role including non-biological parents and step-parents will be able to participate**

AS A THANK YOU

All participants will receive a store gift card at completion of interview to cover costs and as reimbursement for your time

If you are interested in assisting with this research or would like further information you can contact Jenny Davies on 0404 706 788 or email jenny.davies@postgrad.curtin.edu.au

Curtin University Research Ethics Committee (HREC) has approved this study (HRE/2019-0189). Should you wish to discuss the study with someone directly involved, in particular, any matters concerning the conduct of the study or your rights a participant, or wish to make a confidential complaint, you may contact the Ethics Officer on 61+9266 9223 or the Manager, Research integrity on 61+8 29667093 or email hrec@curtin.edu.au

Mothers Facebook Notification, Version 1.2, 17/02/21 (HRE2021-0119).

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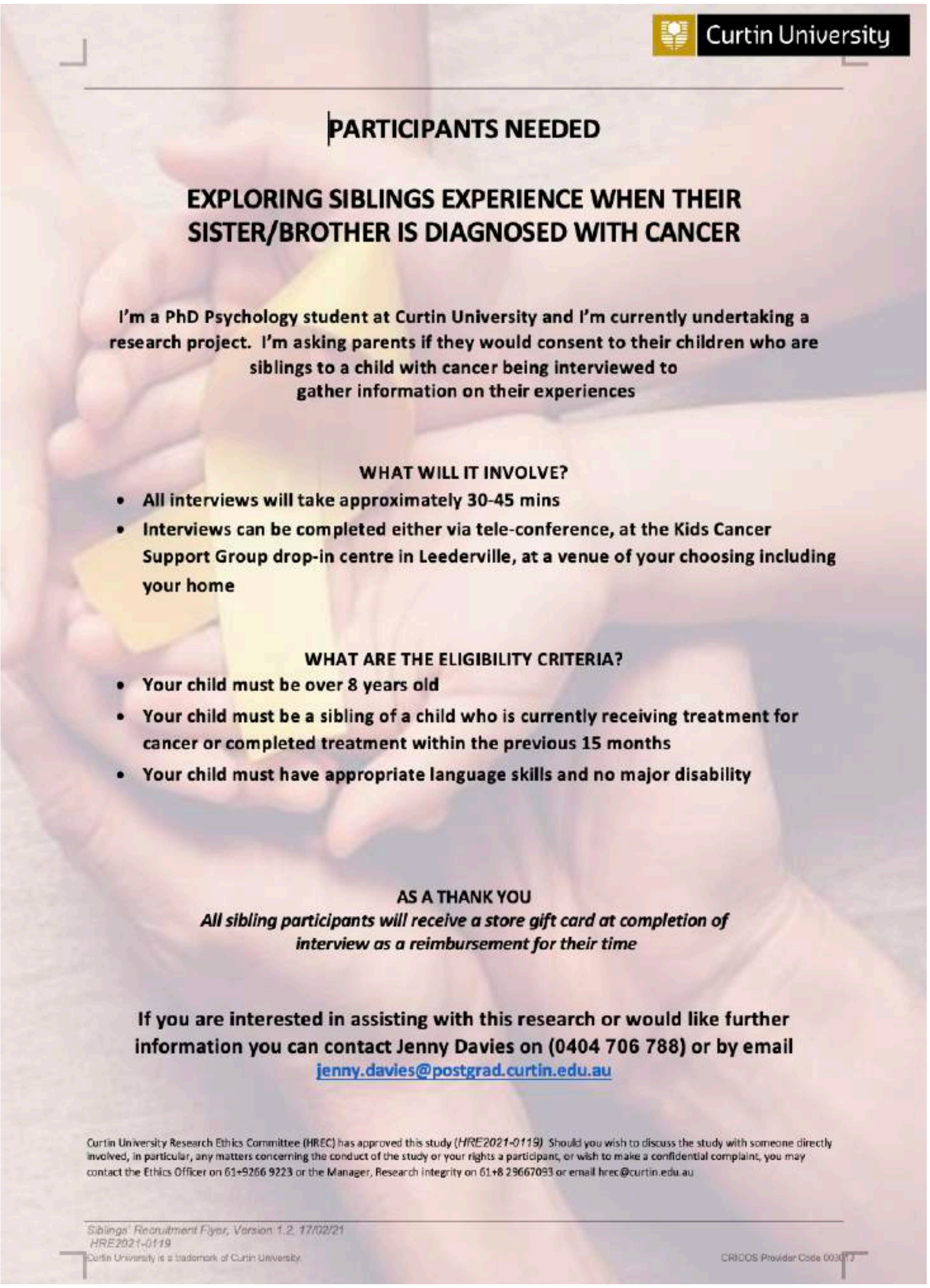
Siblings' recruitment flyer



Curtin University

PARTICIPANTS NEEDED

EXPLORING SIBLINGS EXPERIENCE WHEN THEIR SISTER/BROTHER IS DIAGNOSED WITH CANCER

I'm a PhD Psychology student at Curtin University and I'm currently undertaking a research project. I'm asking parents if they would consent to their children who are siblings to a child with cancer being interviewed to gather information on their experiences

WHAT WILL IT INVOLVE?

- **All interviews will take approximately 30-45 mins**
- **Interviews can be completed either via tele-conference, at the Kids Cancer Support Group drop-in centre in Leederville, at a venue of your choosing including your home**

WHAT ARE THE ELIGIBILITY CRITERIA?

- **Your child must be over 8 years old**
- **Your child must be a sibling of a child who is currently receiving treatment for cancer or completed treatment within the previous 15 months**
- **Your child must have appropriate language skills and no major disability**

AS A THANK YOU

All sibling participants will receive a store gift card at completion of interview as a reimbursement for their time

If you are interested in assisting with this research or would like further information you can contact Jenny Davies on (0404 706 788) or by email jenny.davies@postgrad.curtin.edu.au

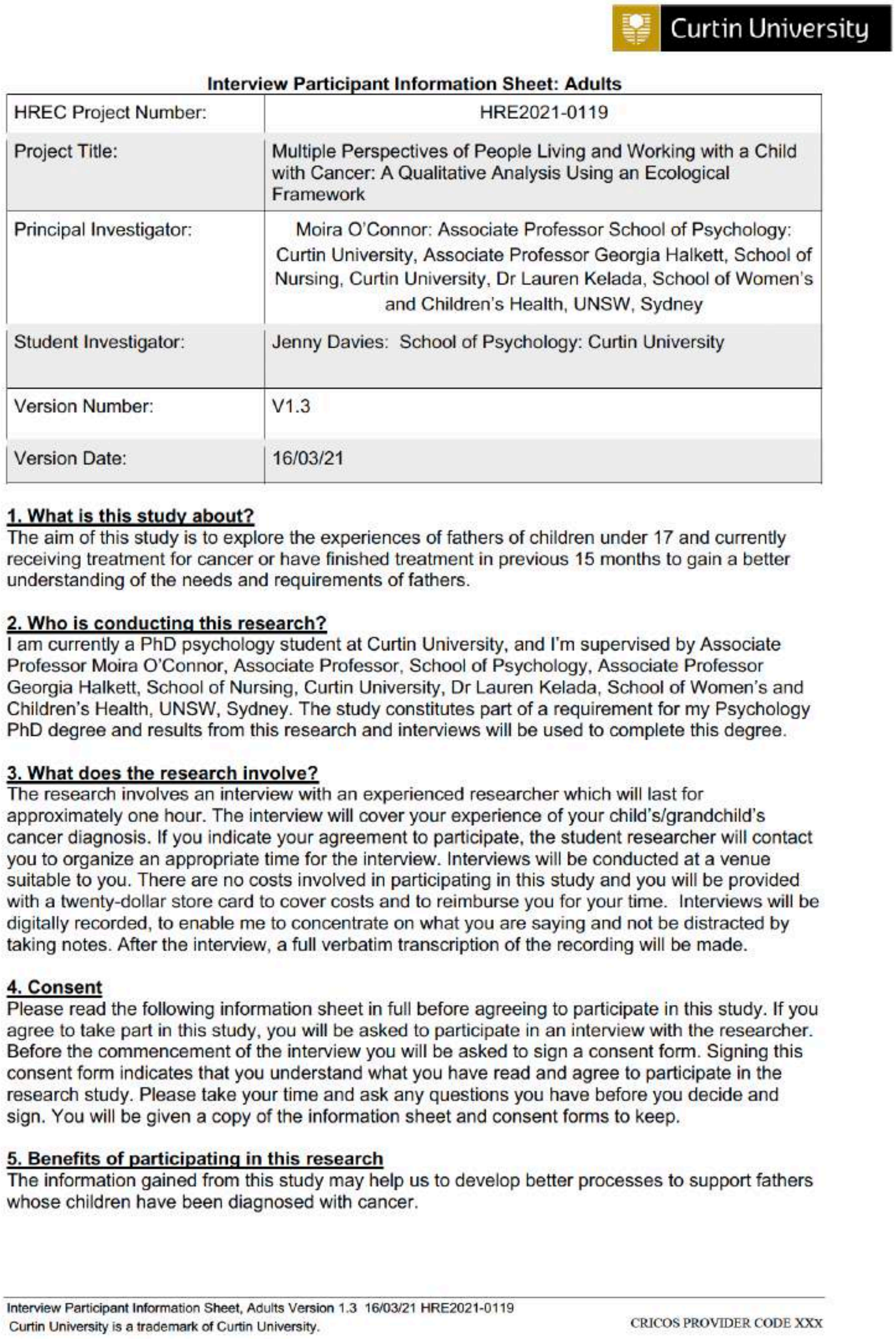
Curtin University Research Ethics Committee (HREC) has approved this study (*HRE2021-0119*) Should you wish to discuss the study with someone directly involved, in particular, any matters concerning the conduct of the study or your rights a participant, or wish to make a confidential complaint, you may contact the Ethics Officer on 61+9266 9223 or the Manager, Research integrity on 61+8 29667093 or email hrec@curtin.edu.au

Siblings' Recruitment Flyer, Version 1.2, 17/02/21
HRE2021-0119

CRICOS Provider Code 00301J

Appendix G: Participant information sheets

Adults' information sheet



Curtin University

Interview Participant Information Sheet: Adults

HREC Project Number:	HRE2021-0119
Project Title:	Multiple Perspectives of People Living and Working with a Child with Cancer: A Qualitative Analysis Using an Ecological Framework
Principal Investigator:	Moira O'Connor: Associate Professor School of Psychology: Curtin University, Associate Professor Georgia Halkett, School of Nursing, Curtin University, Dr Lauren Kelada, School of Women's and Children's Health, UNSW, Sydney
Student Investigator:	Jenny Davies: School of Psychology: Curtin University
Version Number:	V1.3
Version Date:	16/03/21

1. What is this study about?
The aim of this study is to explore the experiences of fathers of children under 17 and currently receiving treatment for cancer or have finished treatment in previous 15 months to gain a better understanding of the needs and requirements of fathers.

2. Who is conducting this research?
I am currently a PhD psychology student at Curtin University, and I'm supervised by Associate Professor Moira O'Connor, Associate Professor, School of Psychology, Associate Professor Georgia Halkett, School of Nursing, Curtin University, Dr Lauren Kelada, School of Women's and Children's Health, UNSW, Sydney. The study constitutes part of a requirement for my Psychology PhD degree and results from this research and interviews will be used to complete this degree.

3. What does the research involve?
The research involves an interview with an experienced researcher which will last for approximately one hour. The interview will cover your experience of your child's/grandchild's cancer diagnosis. If you indicate your agreement to participate, the student researcher will contact you to organize an appropriate time for the interview. Interviews will be conducted at a venue suitable to you. There are no costs involved in participating in this study and you will be provided with a twenty-dollar store card to cover costs and to reimburse you for your time. Interviews will be digitally recorded, to enable me to concentrate on what you are saying and not be distracted by taking notes. After the interview, a full verbatim transcription of the recording will be made.

4. Consent
Please read the following information sheet in full before agreeing to participate in this study. If you agree to take part in this study, you will be asked to participate in an interview with the researcher. Before the commencement of the interview you will be asked to sign a consent form. Signing this consent form indicates that you understand what you have read and agree to participate in the research study. Please take your time and ask any questions you have before you decide and sign. You will be given a copy of the information sheet and consent forms to keep.

5. Benefits of participating in this research
The information gained from this study may help us to develop better processes to support fathers whose children have been diagnosed with cancer.

6. Possible risks of participating in this research

There are minimal risks involved in participating in this study. However, it will involve discussing and sharing your experiences of your child's diagnosis of cancer which be distressing or uncomfortable. If you do feel distressed by any of the questions you can choose not to answer them. At the end of the interview you will be provided with information about a range of support services, so that you can access support if you need it. Accessing these services is purely voluntary and all services are completely confidential. At the completion of the interview you will be asked to complete an Emotional Thermometer tool which is a simple tool designed to rate level of distress and will help to determine if you need additional support. Prior to the interview you will be asked to provide a contact details of a trusted health care professional (for example your GP or Hospital allied health staff). With your permission if after completion of the Emotional Thermometer results indicates you need support the interviewer will contact your health care professional to let them know that you have participated in the study and may need follow-up support.

7. Withdraw from this research study

Your participation in this study is completely voluntary. You do not have to agree to participate, and you can choose not to participate or to withdraw at any time before or during the interview process. You do not have to give a reason just tell the interviewer, that you want to stop. You can also choose to withdraw after the interview by contacting Jenny Davies on details provided and indicating that you no longer wish for you information to be included. Once the interviews have been transcribed and analysed, all identifying information will be removed, and it will not be possible for you to be removed from the research project

8. Privacy and confidentiality

We will only report data in an aggregate (combined) form, and you will not be identified in any specific way and no names will be used in research findings or made available in any public form. Electronic data will be password protected and all hard copy data will be kept in locked storage. The information we collect in this study will be kept under secure conditions at Curtin University for 7 years after the research has ended and then it will be destroyed.

9. Results at the completion of the study

If you would like to be informed of the results of this study, please contact Jenny Davies using the contact details below. Both the completed report and/or a brief overview summary will be available to all participants at the completion of the study. The full results of this research may be presented at conferences or published in professional journals. You will not be individually identified in any results that are published or presented.

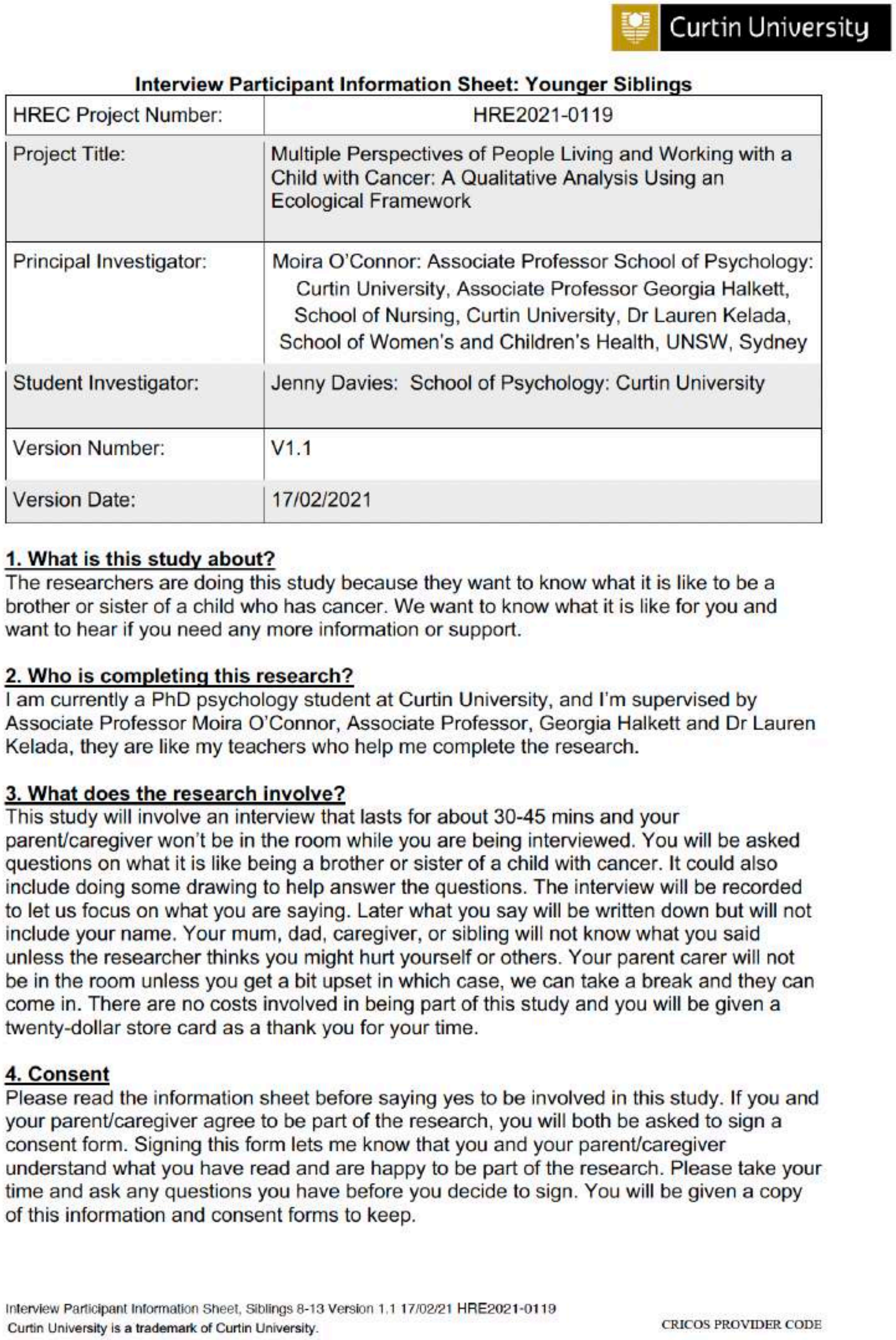
10. Further information

For further information or if you have any questions feel free to email the researcher jenny.davies@postgrad.curtin.edu.au or phone on 0404 706 788. Alternatively, you can contact the Supervisor Associate Professor Moira O'Connor at 9266 3450 or M.Oconnor@curtin.edu.au.

11. Ethical guidelines for this project

Curtin University Human Research Ethics Committee has approved this study (HRE2021-0119). Should you wish to discuss the study with someone not directly involved, in particular relating, to any matters concerning the conduct of the study or your rights as a participant, or if you wish to make a confidential complaint, you can contact the Curtin Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au

Siblings' information sheet



Curtin University

Interview Participant Information Sheet: Younger Siblings

HREC Project Number:	HRE2021-0119
Project Title:	Multiple Perspectives of People Living and Working with a Child with Cancer: A Qualitative Analysis Using an Ecological Framework
Principal Investigator:	Moira O'Connor: Associate Professor School of Psychology: Curtin University, Associate Professor Georgia Halkett, School of Nursing, Curtin University, Dr Lauren Kelada, School of Women's and Children's Health, UNSW, Sydney
Student Investigator:	Jenny Davies: School of Psychology: Curtin University
Version Number:	V1.1
Version Date:	17/02/2021

1. What is this study about?

The researchers are doing this study because they want to know what it is like to be a brother or sister of a child who has cancer. We want to know what it is like for you and want to hear if you need any more information or support.

2. Who is completing this research?

I am currently a PhD psychology student at Curtin University, and I'm supervised by Associate Professor Moira O'Connor, Associate Professor, Georgia Halkett and Dr Lauren Kelada, they are like my teachers who help me complete the research.

3. What does the research involve?

This study will involve an interview that lasts for about 30-45 mins and your parent/caregiver won't be in the room while you are being interviewed. You will be asked questions on what it is like being a brother or sister of a child with cancer. It could also include doing some drawing to help answer the questions. The interview will be recorded to let us focus on what you are saying. Later what you say will be written down but will not include your name. Your mum, dad, caregiver, or sibling will not know what you said unless the researcher thinks you might hurt yourself or others. Your parent carer will not be in the room unless you get a bit upset in which case, we can take a break and they can come in. There are no costs involved in being part of this study and you will be given a twenty-dollar store card as a thank you for your time.

4. Consent

Please read the information sheet before saying yes to be involved in this study. If you and your parent/caregiver agree to be part of the research, you will both be asked to sign a consent form. Signing this form lets me know that you and your parent/caregiver understand what you have read and are happy to be part of the research. Please take your time and ask any questions you have before you decide to sign. You will be given a copy of this information and consent forms to keep.

5. Benefits of participating in this research

There may no direct benefits to you in taking part in the research. But talking to you and developing a better understanding may help us to develop better supports for brothers and sisters of children who have been diagnosed with cancer.

6. Possible risks of participating in this research

There are not many bad things about taking part in this research. But sometimes talking about stuff can be a upsetting. We will also give your mum, dad or caregiver details of places you can contact to ask for some help after the interview if you need to. Accessing these services is your choice and all services are completely confidential.

7. Withdraw from this research study

You don't have to participate in this research. If you do find it difficult you can ask to take a break, (go the toilet or speak to your parent/caregiver) or you can choose to say you don't want to answer some questions or you can stop. You do not have to give us a reason just tell me that you want to stop. You can also choose to stop being part of the research after the interview by contacting me (or getting your parents/carer to) and letting me know that you no longer wish for what you have told me to be included. Once the interviews have been written up, all information that lets us know who you are will be removed, and it will not be possible for you to be removed from the research project

8. Privacy and confidentiality

We will not share the things you talk about with your parents or family unless you tell us something that indicates you might hurt yourself or others. We will only report information in a combined form. You will not be named in any specific way and no names will be used in research findings. Electronic data will be password protected and all hard copy data will be kept in locked cupboard. The information we collect in this study will be kept securely at Curtin University for 25 years after the research has ended and then it will be destroyed.

9. Results after study is completed

If you would like to know about what the final study says, please contact me (or get your parents/carer to) using the details below and I can send you some information to read. The full results of this research may be presented at conferences or published in professional journals.

10. Further information

For further information or if you have any questions feel free to email jenny.davies@postgrad.curtin.edu.au or call 0404 706 788. Alternatively, you can contact the main supervisor Dr Moira O'Connor at 9266 3450 or M.Oconnor@curtin.edu.au.

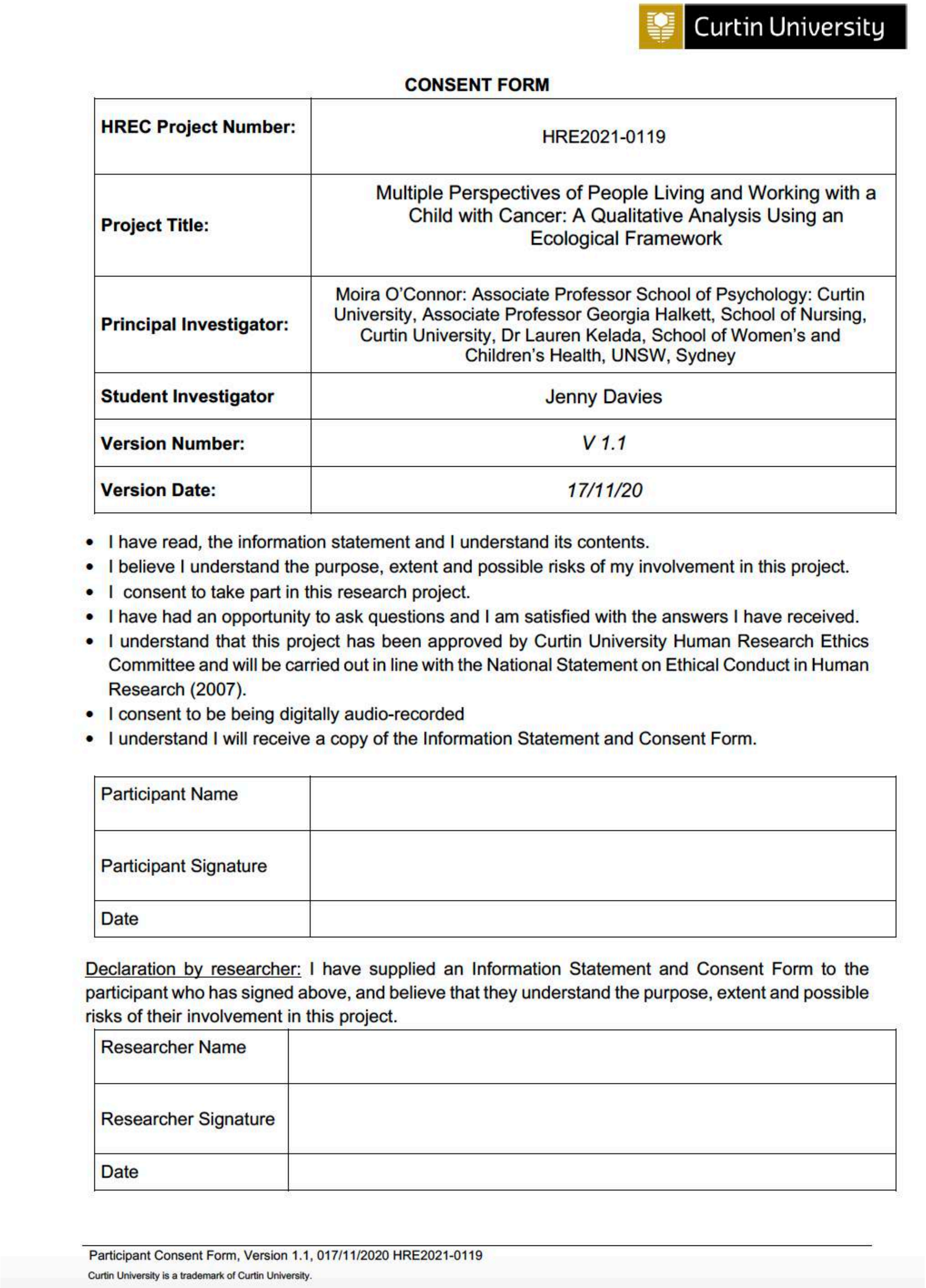
11. Ethical guidelines for this project

Curtin University Human Research Ethics Committee (HREC) has approved this study HRE/2021-0119. Should you wish to discuss the study with someone not directly involved, in particular relating, to any matters concerning the conduct of the study or your rights as a participant, or if you wish to make a confidential complaint, you can contact the Curtin Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au

Thank you for taking time to consider this study

Appendix H: Consent forms

Adults (parents & grandparents) consent form



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CONSENT FORM

HREC Project Number:	HRE2021-0119
Project Title:	Multiple Perspectives of People Living and Working with a Child with Cancer: A Qualitative Analysis Using an Ecological Framework
Principal Investigator:	Moira O'Connor: Associate Professor School of Psychology: Curtin University, Associate Professor Georgia Halkett, School of Nursing, Curtin University, Dr Lauren Kelada, School of Women's and Children's Health, UNSW, Sydney
Student Investigator	Jenny Davies
Version Number:	*V 1.1*
Version Date:	*17/11/20*

- I have read, the information statement and I understand its contents.
- I believe I understand the purpose, extent and possible risks of my involvement in this project.
- I consent to take part in this research project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by Curtin University Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).
- I consent to be being digitally audio-recorded
- I understand I will receive a copy of the Information Statement and Consent Form.

Participant Name	
Participant Signature	
Date	

<u>Declaration by researcher:</u> I have supplied an Information Statement and Consent Form to the participant who has signed above, and believe that they understand the purpose, extent and possible risks of their involvement in this project.

Researcher Name	
Researcher Signature	
Date	

Participant Consent Form, Version 1.1, 017/11/2020 HRE2021-0119

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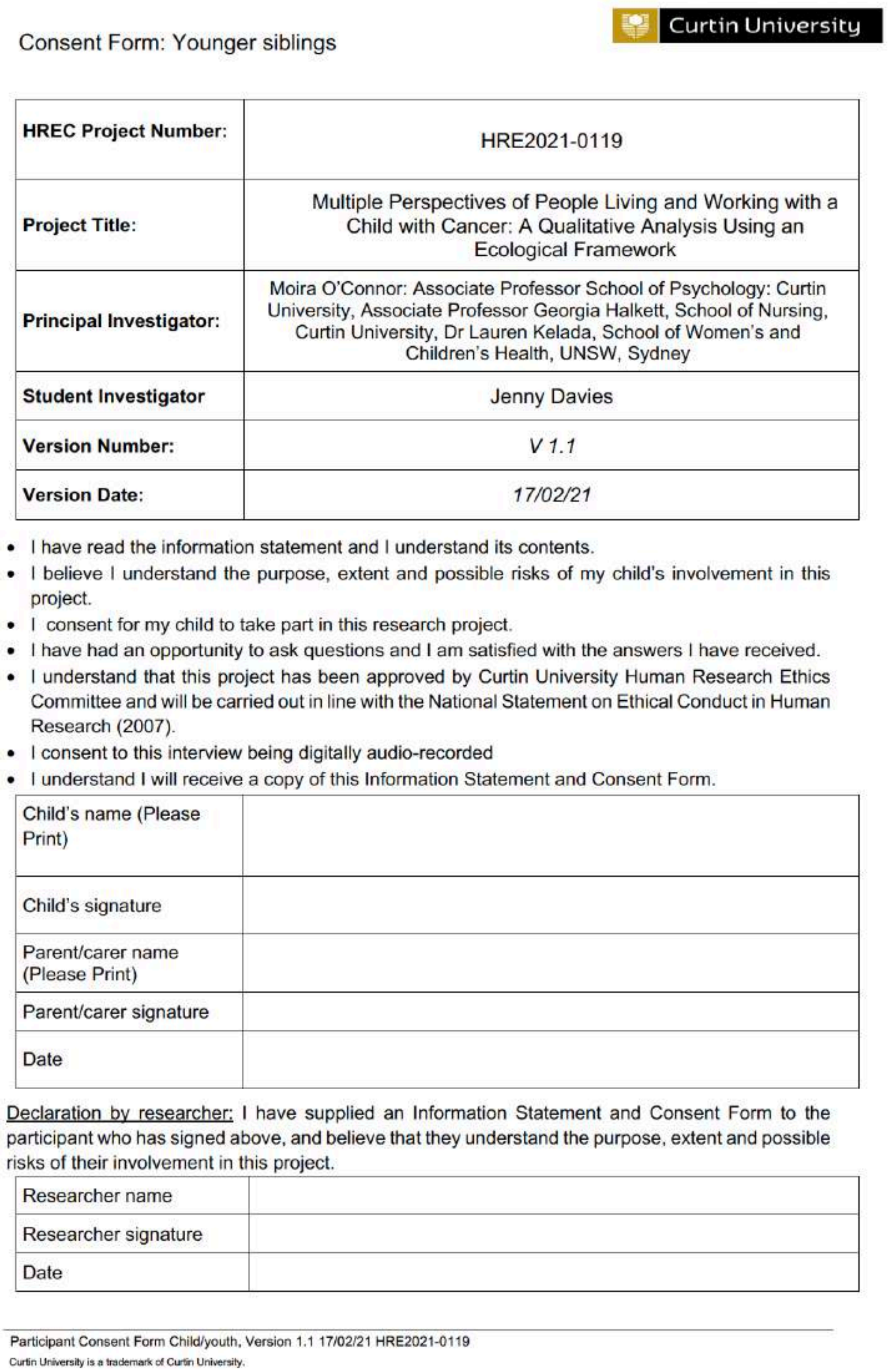
Siblings' consent form



Consent Form: Younger siblings

Curtin University

HREC Project Number:	HRE2021-0119
Project Title:	Multiple Perspectives of People Living and Working with a Child with Cancer: A Qualitative Analysis Using an Ecological Framework
Principal Investigator:	Moira O'Connor: Associate Professor School of Psychology: Curtin University, Associate Professor Georgia Halkett, School of Nursing, Curtin University, Dr Lauren Kelada, School of Women's and Children's Health, UNSW, Sydney
Student Investigator	Jenny Davies
Version Number:	*V 1.1*
Version Date:	*17/02/21*

- I have read the information statement and I understand its contents.
- I believe I understand the purpose, extent and possible risks of my child's involvement in this project.
- I consent for my child to take part in this research project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by Curtin University Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).
- I consent to this interview being digitally audio-recorded
- I understand I will receive a copy of this Information Statement and Consent Form.

Child's name (Please Print)	
Child's signature	
Parent/carer name (Please Print)	
Parent/carer signature	
Date	

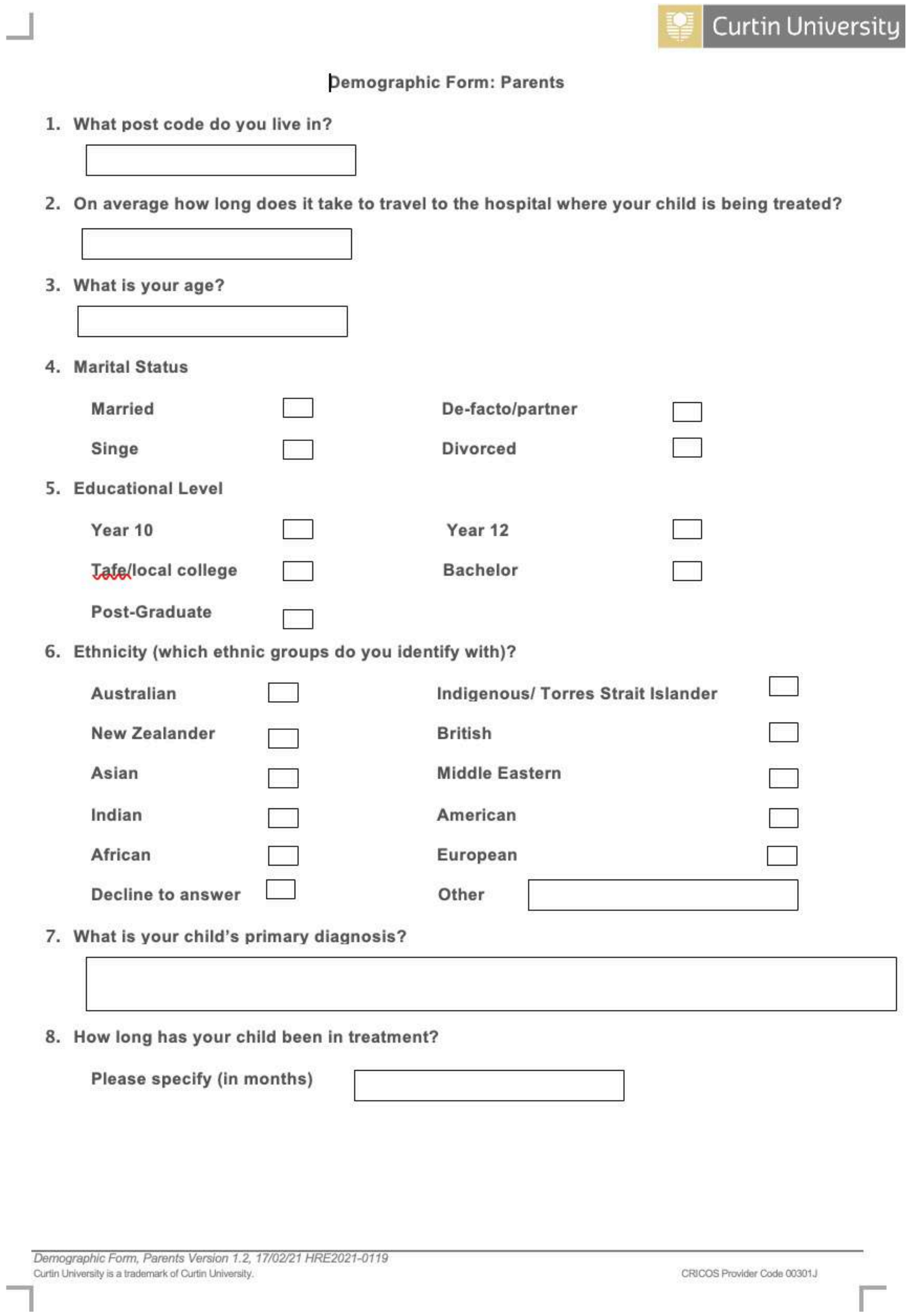
<u>Declaration by researcher:</u> I have supplied an Information Statement and Consent Form to the participant who has signed above, and believe that they understand the purpose, extent and possible risks of their involvement in this project.

Researcher name	
Researcher signature	
Date	

Participant Consent Form Child/youth, Version 1.1 17/02/21 HRE2021-0119

Appendix I: Demographic forms

Parents' demographic form



Curtin University

Demographic Form: Parents

1. What post code do you live in?

☐

2. On average how long does it take to travel to the hospital where your child is being treated?

☐

3. What is your age?

☐

4. Marital Status

Married	☐	De-facto/partner	☐
Singe	☐	Divorced	☐

5. Educational Level

Year 10	☐	Year 12	☐
Tafe/local college	☐	Bachelor	☐
Post-Graduate	☐		

6. Ethnicity (which ethnic groups do you identify with)?

Australian	☐	Indigenous/ Torres Strait Islander	☐
New Zealander	☐	British	☐
Asian	☐	Middle Eastern	☐
Indian	☐	American	☐
African	☐	European	☐
Decline to answer	☐	Other	☐

7. What is your child's primary diagnosis?

☐

8. How long has your child been in treatment?

Please specify (in months) ☐

Demographic Form, Parents Version 1.2, 17/02/21 HRE2021-0119

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CRICOS Provider Code 00301J

9. What was your work status when your child was diagnosed?

Full time	☐	Stay at home parent	☐
Part-time	☐	Parental Leave	☐
Casual	☐	Carer	☐
Student	☐	Other	☐

10. Did you change your work status as a result of your child's treatment?

Yes ☐ No ☐ If yes (please specify why below)

☐

What is your current work status?

Full time	☐	Stay at home parent	☐
Part-time	☐	Parental Leave	☐
Casual	☐	Carer	☐
Student	☐	Other	☐

11. How many siblings does the child diagnosed with cancer have?

None	☐	One	☐	Two	☐
Three	☐	More than four	☐		

12. If your child with cancer has siblings does anyone assist with the care of the siblings? (please tick all that are relevant with approximate percentage)

No siblings ☐

Grandparents	☐	________	Neighbours	☐	________
Friends	☐	________	Extended family	☐	________

Formal childcare/afterschool ☐ ________

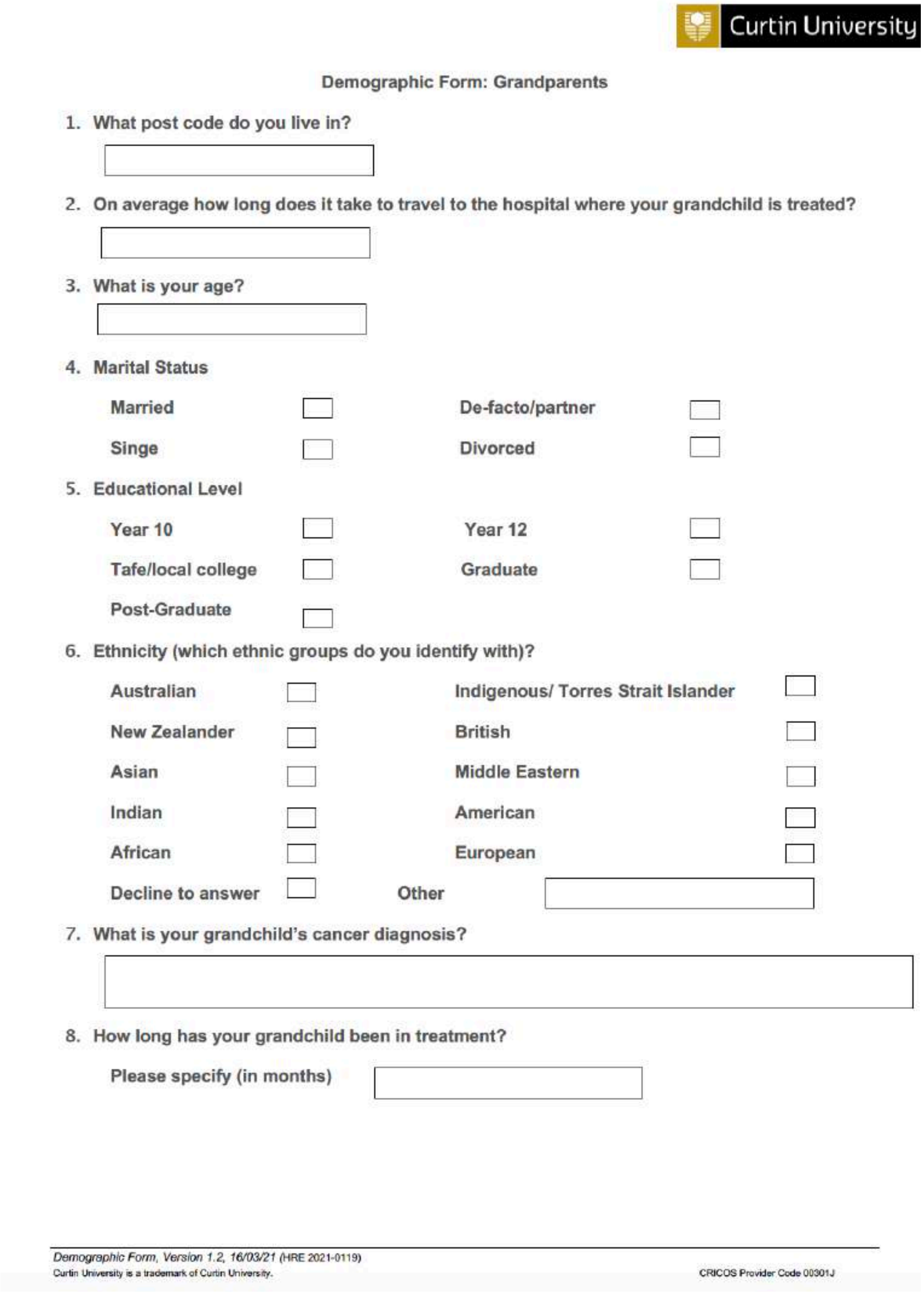
Other (please specify) ☐ ________

13. Was your child in school at diagnosis? If so please specify what grade in box below

Yes ☐ No ☐ ☐

14. What grade is your child currently in at school? (NA if not applicable) ☐

Grandparents' demographic form



Curtin University

Demographic Form: Grandparents

1. What post code do you live in?

2. On average how long does it take to travel to the hospital where your grandchild is treated?

3. What is your age?

4. Marital Status

   Married ☐
   Singe ☐
   De-facto/partner ☐
   Divorced ☐

5. Educational Level

   Year 10 ☐
   Tafe/local college ☐
   Post-Graduate ☐
   Year 12 ☐
   Graduate ☐

6. Ethnicity (which ethnic groups do you identify with)?

   Australian ☐
   New Zealander ☐
   Asian ☐
   Indian ☐
   African ☐
   Decline to answer ☐
   Indigenous/ Torres Strait Islander ☐
   British ☐
   Middle Eastern ☐
   American ☐
   European ☐
   Other

7. What is your grandchild's cancer diagnosis?

8. How long has your grandchild been in treatment?

   Please specify (in months)

Demographic Form, Version 1.2, 16/03/21 (HRE 2021-0119)

Curtin University is a trademark of Curtin University.

CRICOS Provider Code 00301J

9. What was your work status when your grandchild was diagnosed?

Full time ☐
Part-time ☐
Casual ☐
Student ☐
Other ☐

Homemaker ☐
Retired ☐
Carer ☐

10. Did you change your work status as a result of your grandchild's treatment?

Yes ☐ No ☐

If yes why ☐

11. What is your current work status?

Full time ☐
Part-time ☐
Casual ☐
Student ☐

Homemaker ☐
Retired ☐
Carer ☐
Other ☐

12. How many siblings does the grandchild diagnosed with cancer have?

None ☐
Three ☐

One ☐
More than four ☐

Two ☐

13. Was your grandchild in school at diagnosis? If so please specify grade in the box below

Yes ☐ No ☐ ☐

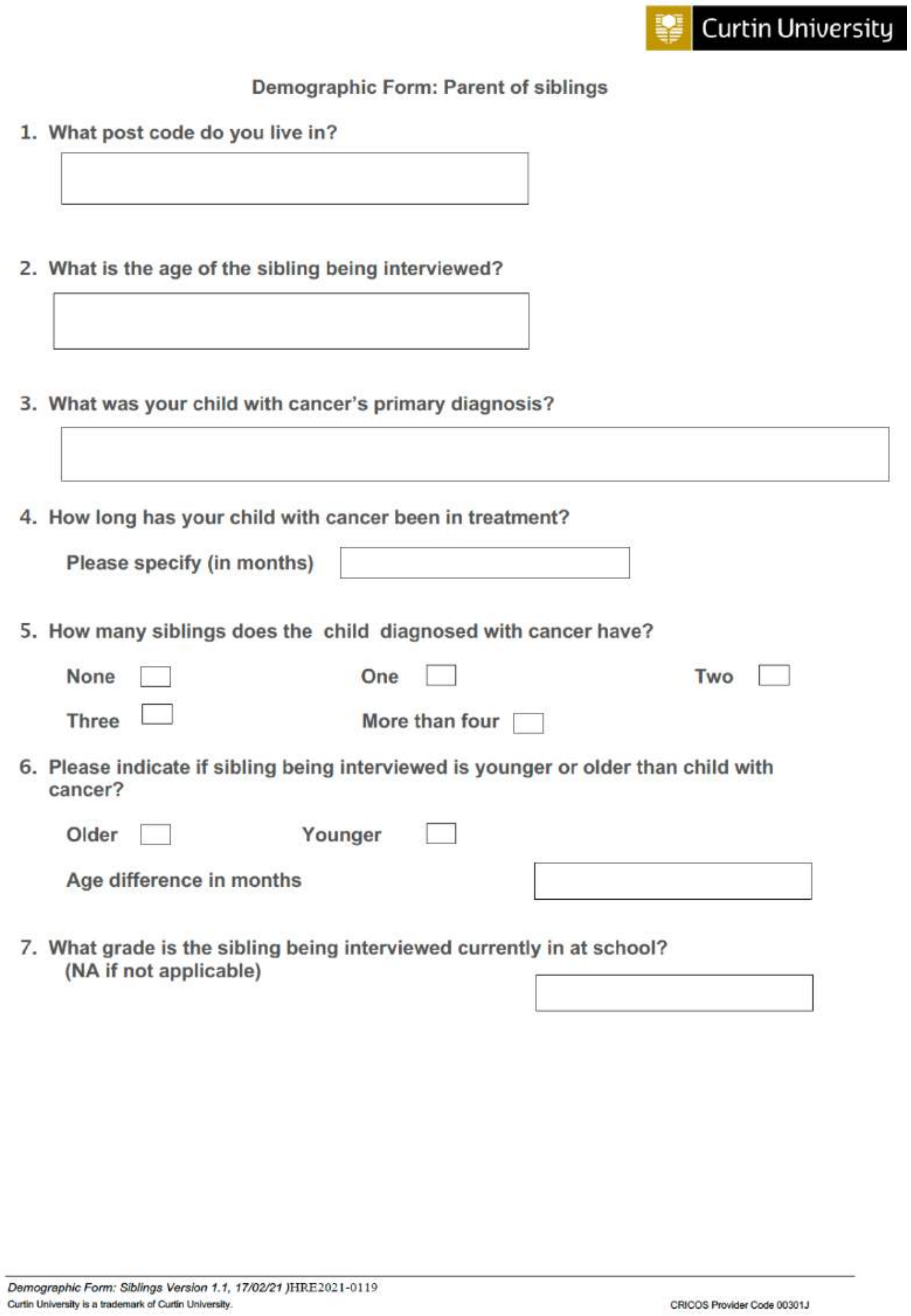
14. What grade is your grandchild currently in at school? (NA if not applicable) ☐

15. Do you assist in care for either the child or their sibling/s (if so please indicate on average how often you assist?

Yes ☐
Daily ☐
Once or twice a month ☐

No ☐
Once or twice a week ☐
Occasionally ☐

Siblings’ demographic form



Curtin University

Demographic Form: Parent of siblings

1. What post code do you live in?

2. What is the age of the sibling being interviewed?

3. What was your child with cancer’s primary diagnosis?

4. How long has your child with cancer been in treatment?

   Please specify (in months)

5. How many siblings does the child diagnosed with cancer have?

   None ☐ One ☐ Two ☐

   Three ☐ More than four ☐

6. Please indicate if sibling being interviewed is younger or older than child with cancer?

   Older ☐ Younger ☐

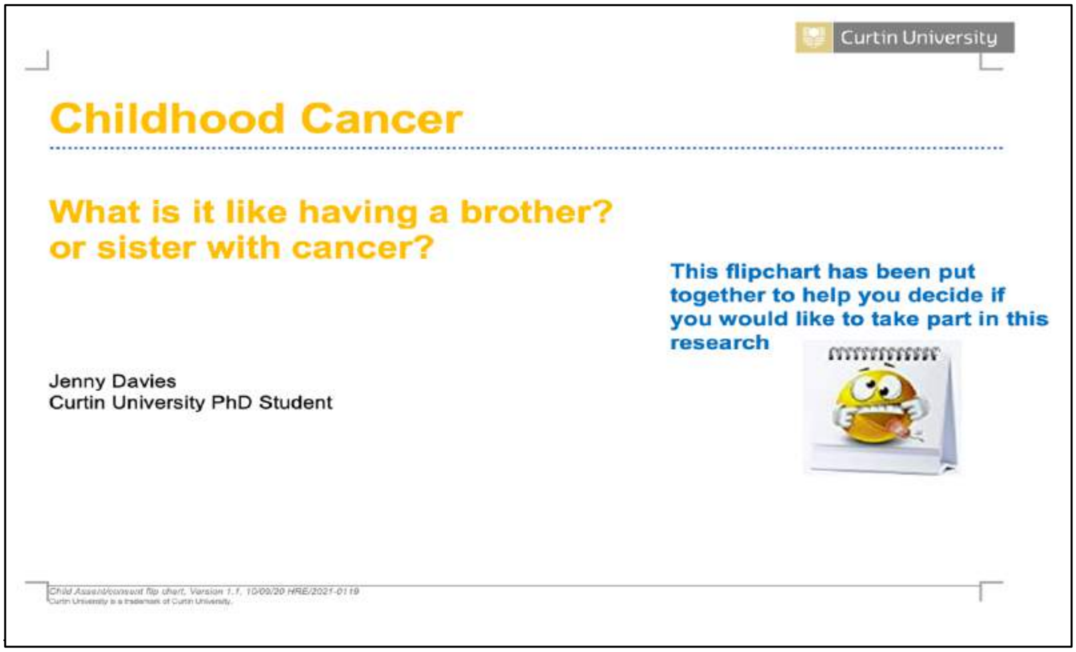
   Age difference in months

7. What grade is the sibling being interviewed currently in at school? (NA if not applicable)

Demographic Form: Siblings Version 1.1, 17/02/21 JHRE2021-0119

CRICOS Provider Code 00301J

Appendix J: Siblings' flip chart consent form



Curtin University

Childhood Cancer

What is it like having a brother? or sister with cancer?

This flipchart has been put together to help you decide if you would like to take part in this research

Jenny Davies
Curtin University PhD Student

Child Assent/consent flip chart, Version 1.1, 10/09/20 HRE/2021-0119
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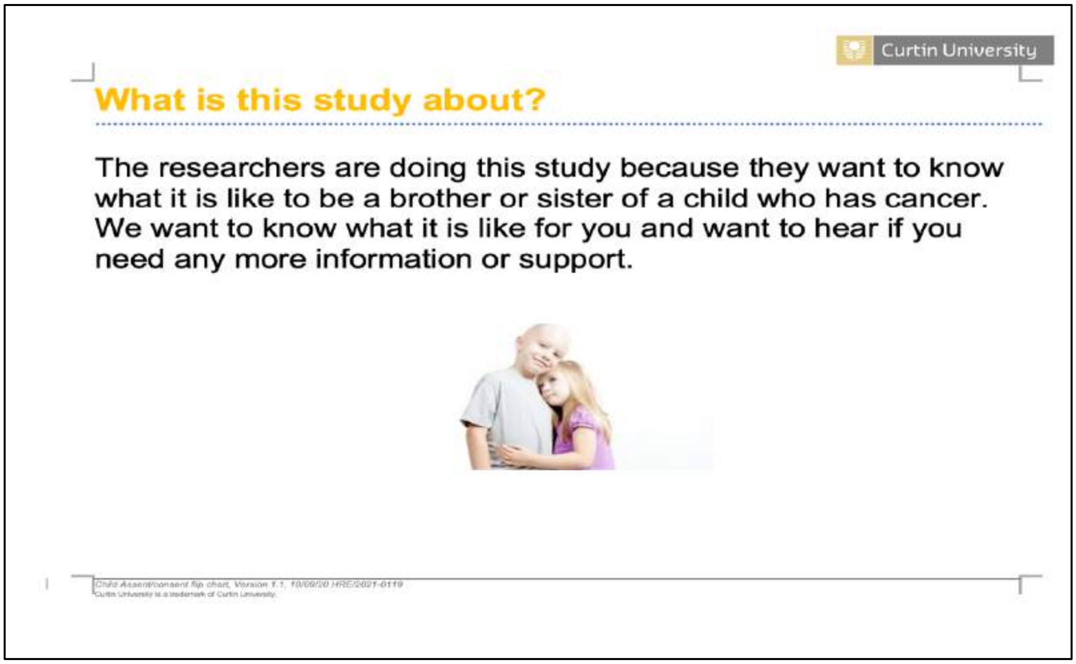

Curtin University

What is this study about?

The researchers are doing this study because they want to know what it is like to be a brother or sister of a child who has cancer. We want to know what it is like for you and want to hear if you need any more information or support.

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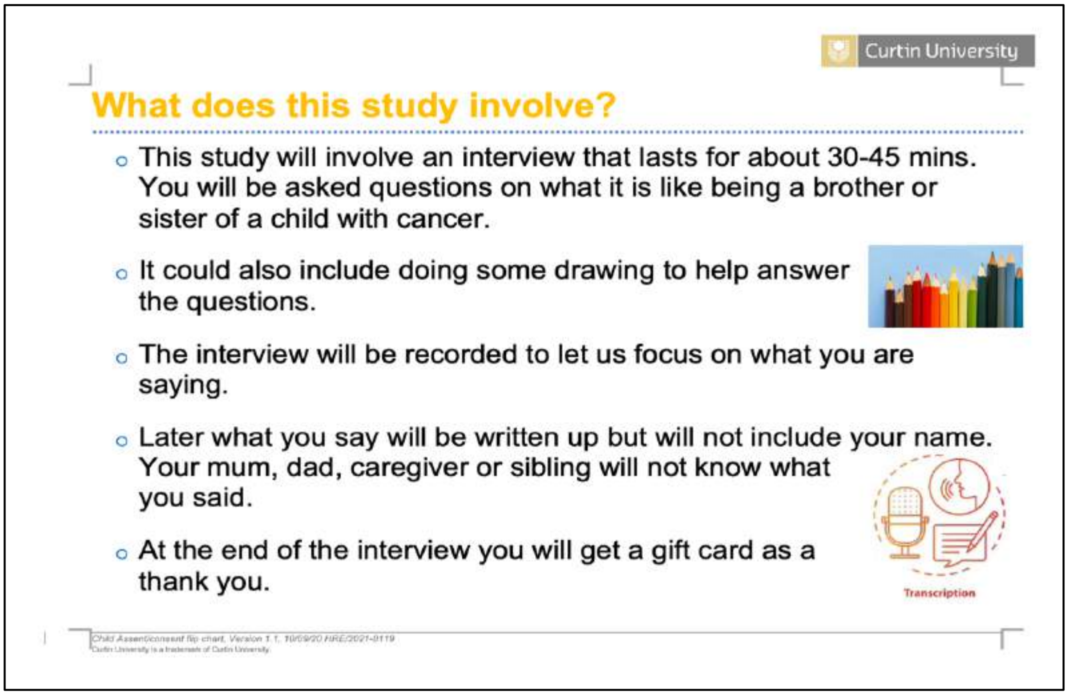
Curtin University is a trademark of Curtin University.

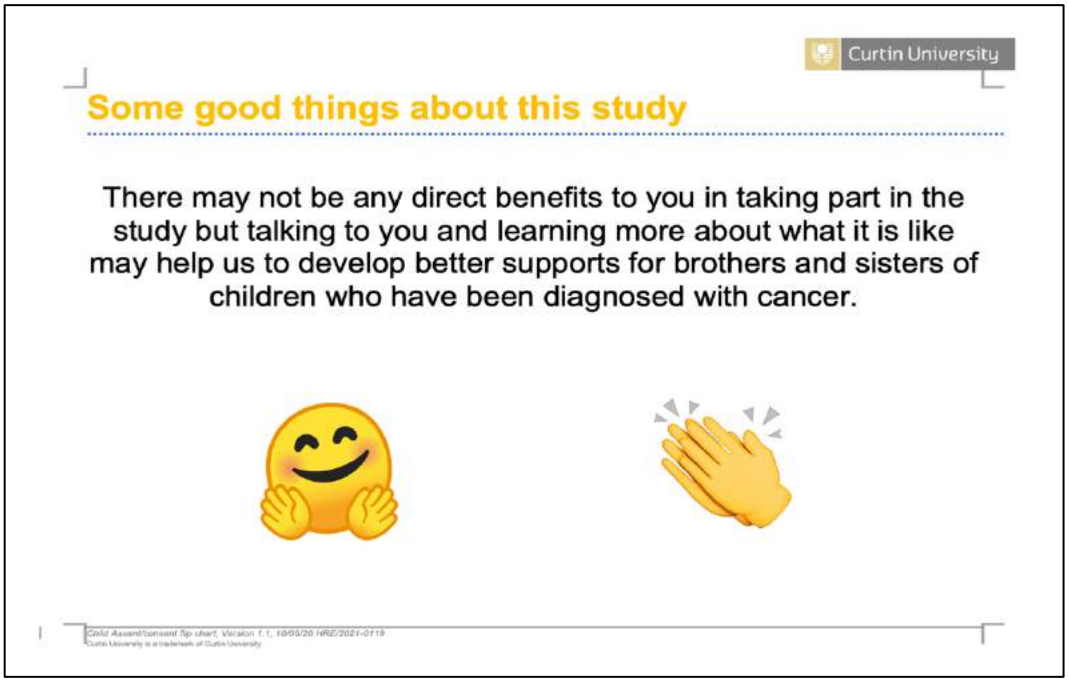


Curtin University

What does this study involve?

- This study will involve an interview that lasts for about 30-45 mins. You will be asked questions on what it is like being a brother or sister of a child with cancer.
- It could also include doing some drawing to help answer the questions.
- The interview will be recorded to let us focus on what you are saying.
- Later what you say will be written up but will not include your name. Your mum, dad, caregiver or sibling will not know what you said.
- At the end of the interview you will get a gift card as a thank you.

Child Assent/consent flip chart, Version 1.1, 10/09/20 HRE2021-0119
Curtin University is a trademark of Curtin University.



Curtin University

Some good things about this study

There may not be any direct benefits to you in taking part in the study but talking to you and learning more about what it is like may help us to develop better supports for brothers and sisters of children who have been diagnosed with cancer.

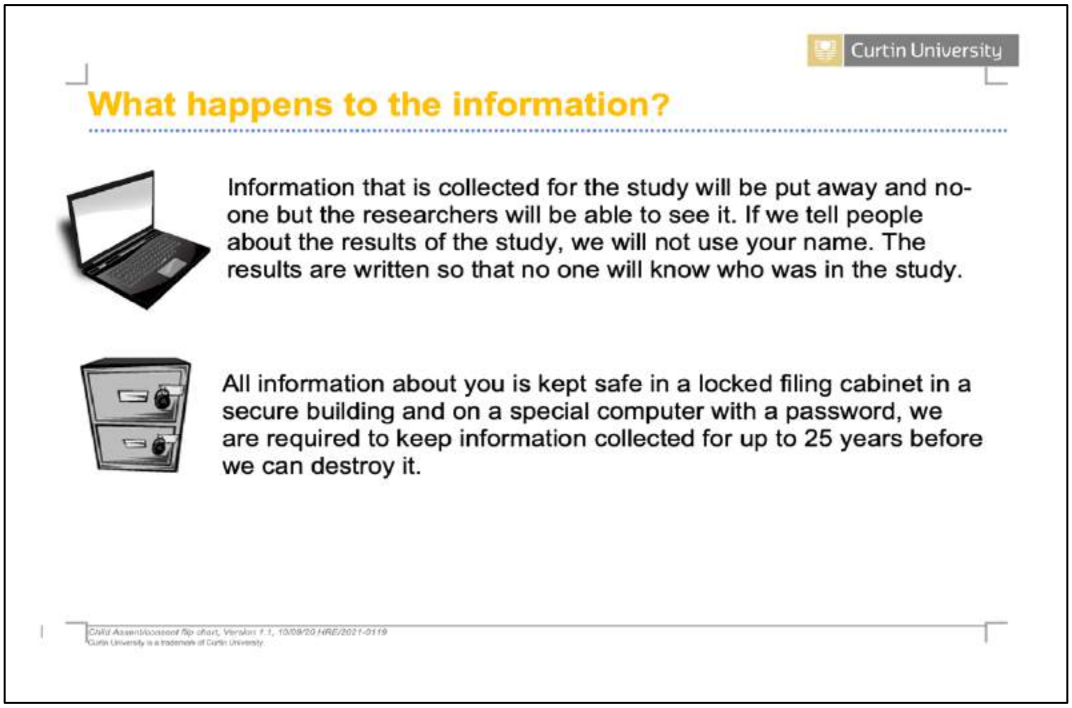
Child Assent/consent flip chart, Version 1.1, 10/09/20 HRE/2021-0119
Curtin University is a trademark of Curtin University.

Some not so good things about this study

There are not many bad things about taking part in this research. But sometimes talking about stuff can be a bit upsetting. If you do find it difficult you can stop at any point or can ask to take a break. We will also give your mum, dad or caregiver details of places you can contact to ask for some help after the interview if you need to.

Consent

We would like to talk with you and your mum, dad or caregiver about the study, if everyone agrees then we will sign a form saying that everyone is happy for you to be included in this study.



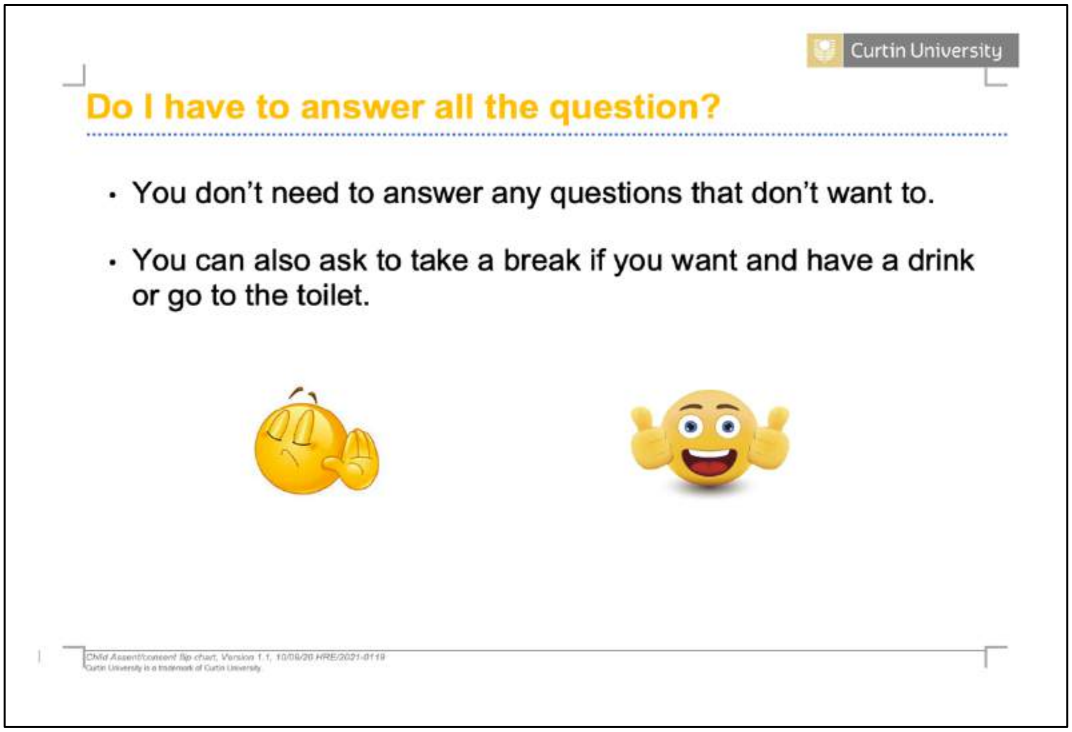
Curtin University

What happens to the information?

Information that is collected for the study will be put away and no-one but the researchers will be able to see it. If we tell people about the results of the study, we will not use your name. The results are written so that no one will know who was in the study.

All information about you is kept safe in a locked filing cabinet in a secure building and on a special computer with a password, we are required to keep information collected for up to 25 years before we can destroy it.

Child Assent/consent flip chart, Version 1.1, 10/09/20 HRE/2021-0119
Curtin University is a trademark of Curtin University.

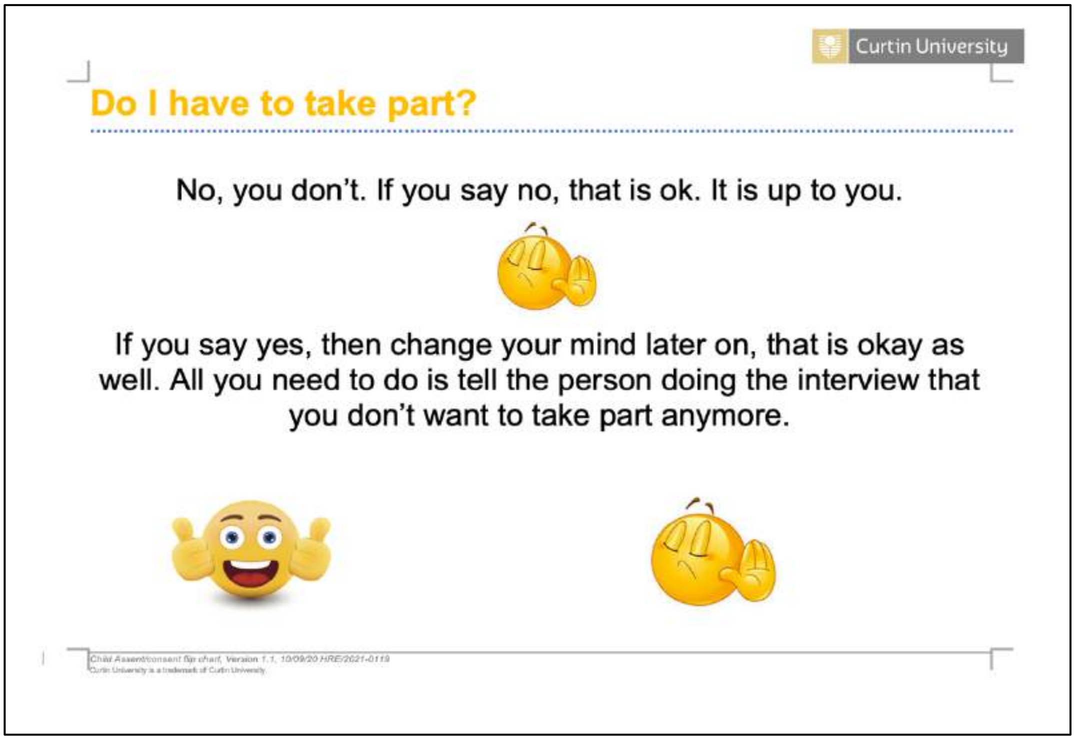


Curtin University

Do I have to answer all the question?

- You don't need to answer any questions that don't want to.
- You can also ask to take a break if you want and have a drink or go to the toilet.

Child Assent/consent flip chart, Version 1.1, 10/09/20 HRE/2021-0119
Curtin University is a trademark of Curtin University.

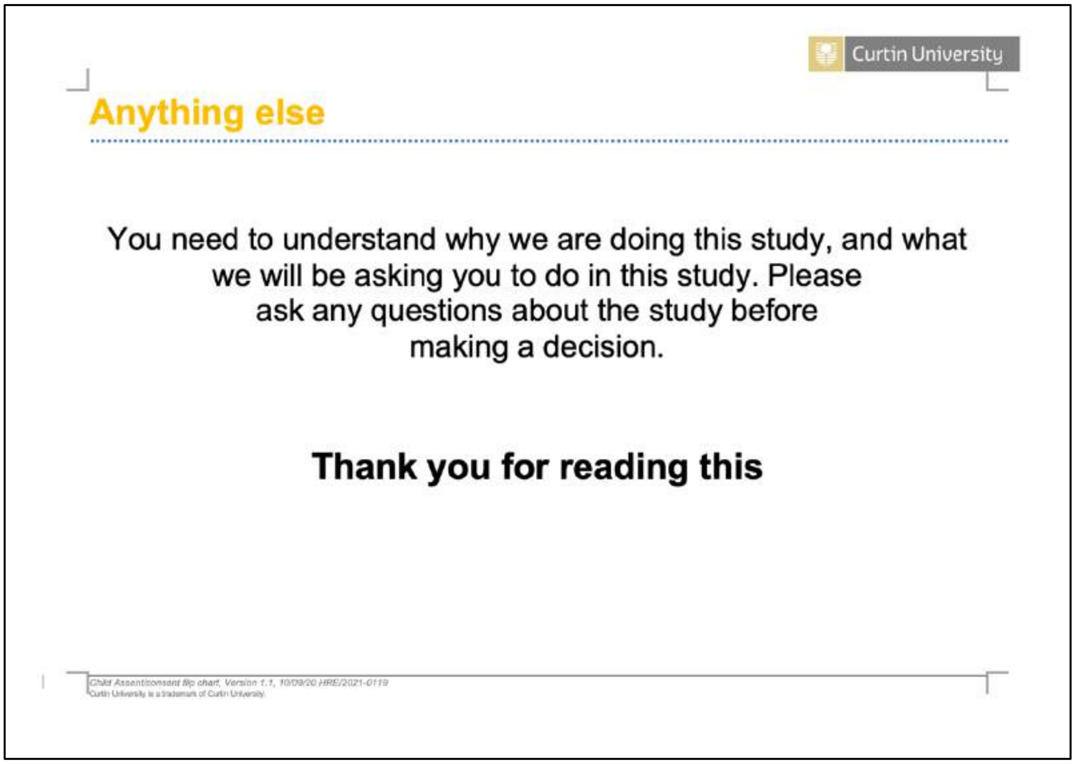


Do I have to take part?

No, you don't. If you say no, that is ok. It is up to you.

If you say yes, then change your mind later on, that is okay as well. All you need to do is tell the person doing the interview that you don't want to take part anymore.

Child Assent/consent flip chart, Version 1.1, 10/09/20 HRE/2021-0119
Curtin University is a trademark of Curtin University.



Anything else

You need to understand why we are doing this study, and what we will be asking you to do in this study. Please ask any questions about the study before making a decision.

Thank you for reading this

Child Assent/consent flip chart, Version 1.1, 10/09/20 HRE/2021-0119
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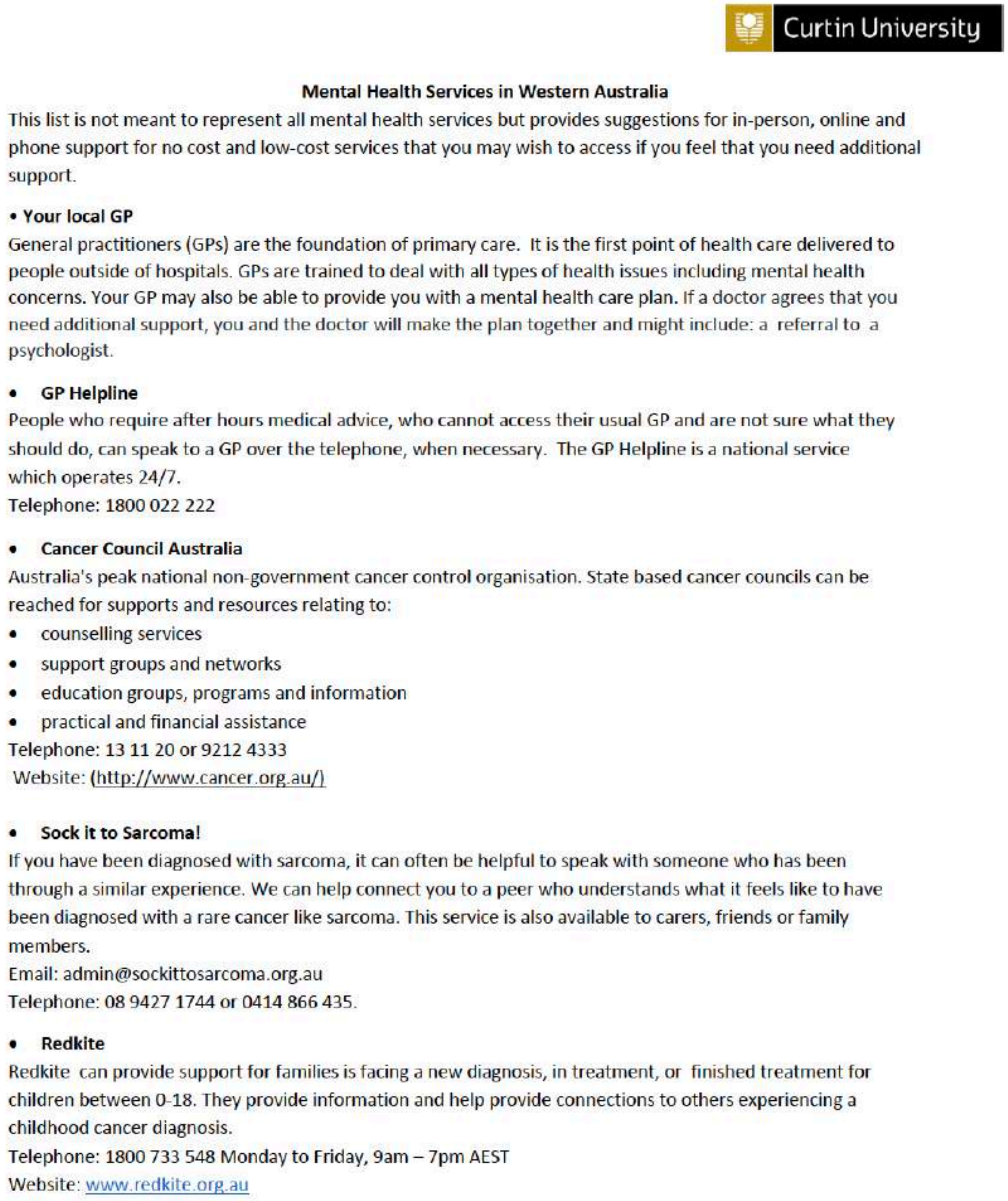
Appendix K: Support services

Adults



Curtin University

Mental Health Services in Western Australia

This list is not meant to represent all mental health services but provides suggestions for in-person, online and phone support for no cost and low-cost services that you may wish to access if you feel that you need additional support.

- **Your local GP**

General practitioners (GPs) are the foundation of primary care. It is the first point of health care delivered to people outside of hospitals. GPs are trained to deal with all types of health issues including mental health concerns. Your GP may also be able to provide you with a mental health care plan. If a doctor agrees that you need additional support, you and the doctor will make the plan together and might include: a referral to a psychologist.

- **GP Helpline**

People who require after hours medical advice, who cannot access their usual GP and are not sure what they should do, can speak to a GP over the telephone, when necessary. The GP Helpline is a national service which operates 24/7.

Telephone: 1800 022 222

- **Cancer Council Australia**

Australia's peak national non-government cancer control organisation. State based cancer councils can be reached for supports and resources relating to:

- counselling services
- support groups and networks
- education groups, programs and information
- practical and financial assistance

Telephone: 13 11 20 or 9212 4333

Website: (http://www.cancer.org.au/)

- **Sock it to Sarcoma!**

If you have been diagnosed with sarcoma, it can often be helpful to speak with someone who has been through a similar experience. We can help connect you to a peer who understands what it feels like to have been diagnosed with a rare cancer like sarcoma. This service is also available to carers, friends or family members.

Email: admin@sockittosarcoma.org.au

Telephone: 08 9427 1744 or 0414 866 435.

- **Redkite**

Redkite can provide support for families is facing a new diagnosis, in treatment, or finished treatment for children between 0-18. They provide information and help provide connections to others experiencing a childhood cancer diagnosis.

Telephone: 1800 733 548 Monday to Friday, 9am – 7pm AEST

Website: www.redkite.org.au

- **BlackDog**

The Black Dog Institute brings together the strength of a medical research institute and a not-for-profit. We are dedicated to understanding, preventing and treating the significant mental health challenges.
Website:⍰http://www.blackdoginstitute.org.au/
Telephone: (02) 9382 2991

- **Beyond Blue**

A national, independent, not-for-profit organisation working to address issues associated with depression and anxiety in Australia. This is a very informative website and includes a 'self-assessment' check sheet for depression which you can print out and take to your GP.
Telephone: 1300 224 636.
Website: www.beyondblue.org.au

24 HOUR TELEPHONE COUNSELLING SERVICES

- **Lifeline:** (08) 13 11 14

Provides a telephone counselling service.

- **Crisis Care:** 9223 1111 or free call 1800 199 008

Crisis Care is a telephone information and counselling service for people in crisis needing urgent help.
Telephone Crisis Care when:

- you need someone to help sort out a serious problem
- you are concerned about the wellbeing of a child
- arguments are causing unhappiness and problems in your family
- you are alone or afraid and urgently need to talk to someone
- you need counselling, information or other support

- **The Samaritans Crisis Line:** 135 247

Provides a crisis telephone service which offers anonymous, non-judgemental, non-religious emotional support, from appropriately trained individuals.

ONLINE SUPPORT SERVICES

- **Mood Gym**: https://moodgym.anu.edu.au/welcome

Provides a free self-help program to teach cognitive behaviour therapy skills to people vulnerable to depression and anxiety.

- **E-couch**: https://ecouch.anu.edu.au/welcome

E-couch is a self-help interactive program with modules for depression, generalised anxiety and worry, social anxiety, relationship breakdown, and loss & grief.

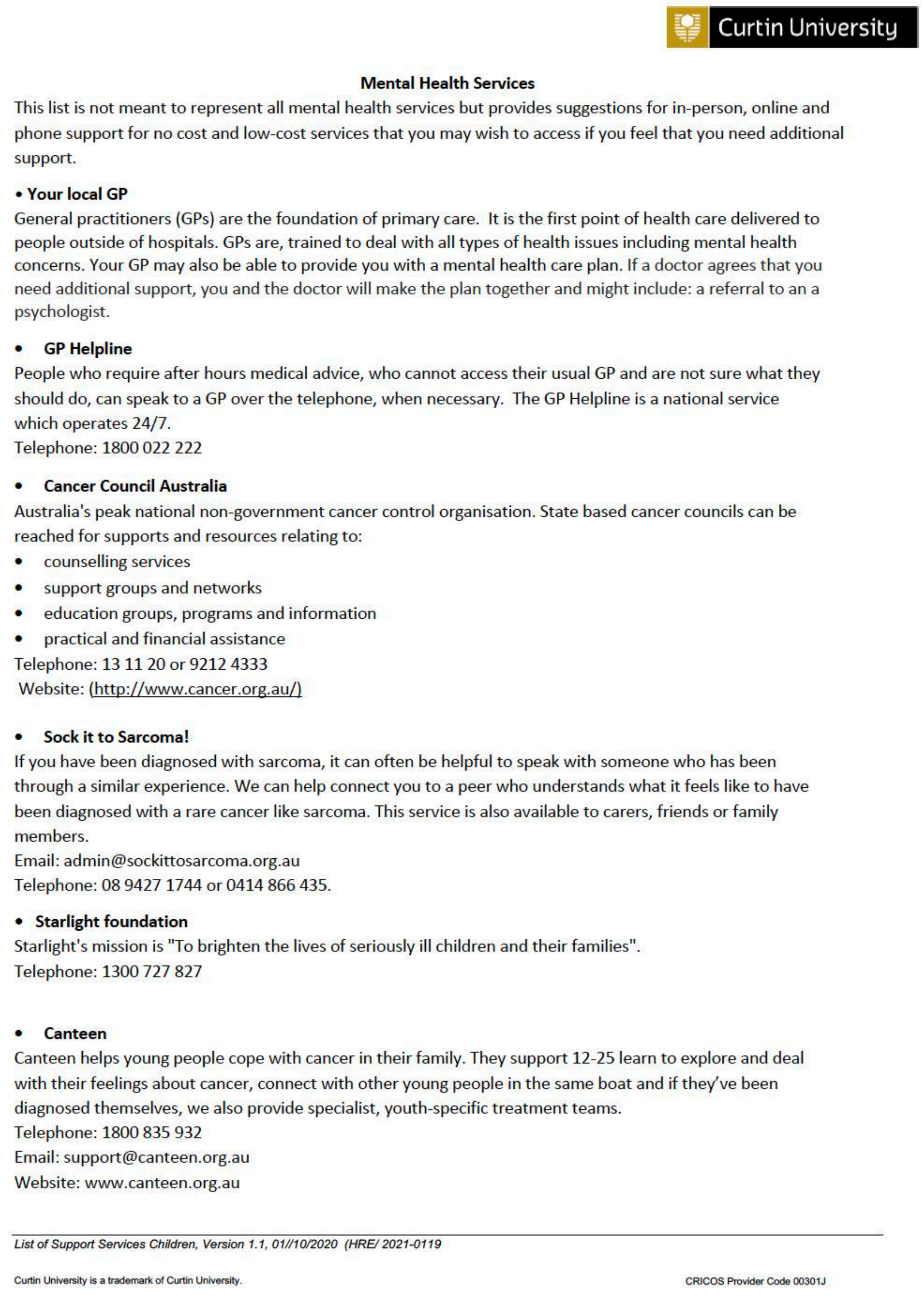
Suicide Call Back Service: http://www.suicidecallbackservice.org.au Telephone: 1300 659 467

- In addition to their crisis support telephone service, the Suicide Call Back Service website offers a number of online resources for those affected by suicide.

- **depressioNet:** http://depressionet.org.au

The purpose of depressioNet.com.au is to empower people experiencing depression to make informed choices and find solutions to the challenges of living with depression.

Siblings support services



Curtin University

Mental Health Services

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- **GP Helpline**

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Telephone: 13 11 20 or 9212 4333
Website: (http://www.cancer.org.au/)

- **Sock it to Sarcoma!**

If you have been diagnosed with sarcoma, it can often be helpful to speak with someone who has been through a similar experience. We can help connect you to a peer who understands what it feels like to have been diagnosed with a rare cancer like sarcoma. This service is also available to carers, friends or family members.
Email: admin@sockittosarcoma.org.au
Telephone: 08 9427 1744 or 0414 866 435.

- **Starlight foundation**

Starlight's mission is "To brighten the lives of seriously ill children and their families".
Telephone: 1300 727 827

- **Canteen**

Canteen helps young people cope with cancer in their family. They support 12-25 learn to explore and deal with their feelings about cancer, connect with other young people in the same boat and if they've been diagnosed themselves, we also provide specialist, youth-specific treatment teams.
Telephone: 1800 835 932
Email: support@canteen.org.au
Website: www.canteen.org.au

List of Support Services Children, Version 1.1, 01//10/2020 (HRE/ 2021-0119

CRICOS Provider Code 00301J

- **Redkite**

Redkite can provide support for families is facing a new diagnosis, in treatment, or finished treatment for children between 0-18. They provide information and help provide connections to others experiencing a childhood cancer diagnosis. They can provide counselling services to help with adjusting to a cancer diagnosis and managing emotions.
Telephone: 1800 733 548 Monday to Friday, 9am – 7pm AEST
Website: www.redkite.org.au

- **Headspace**

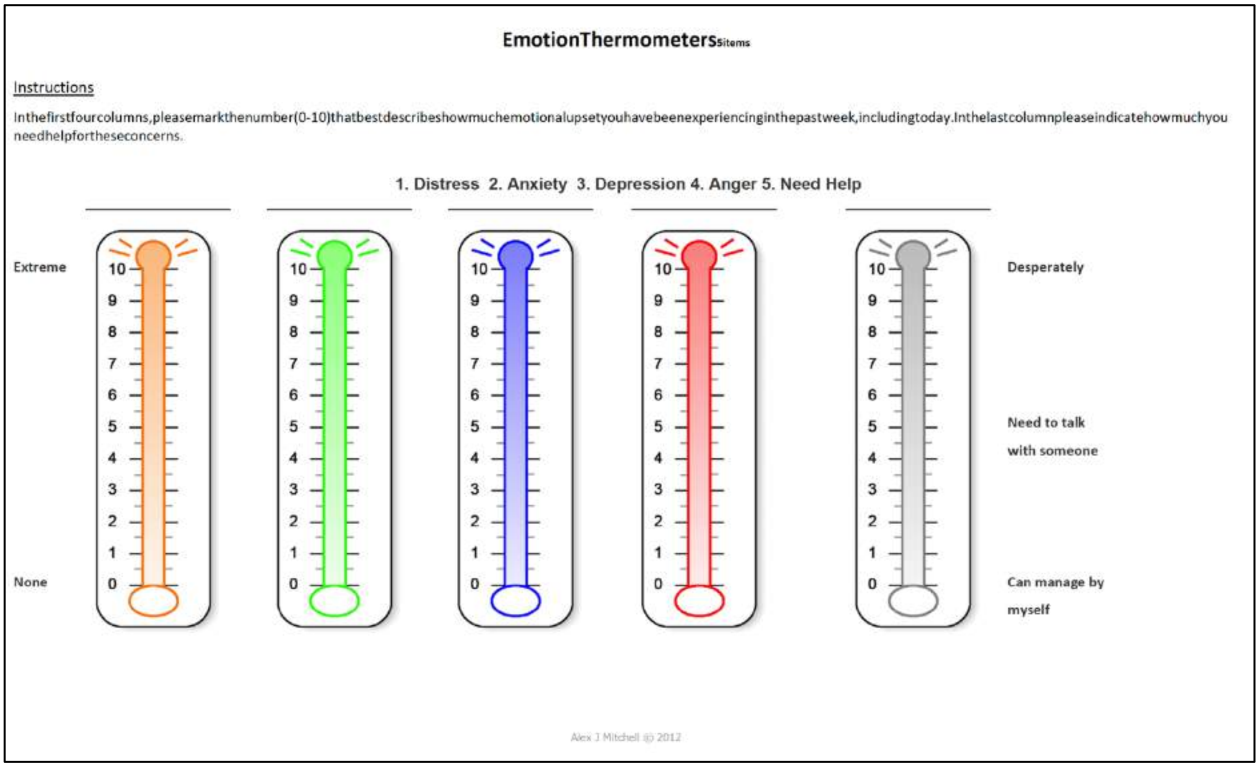
Headspace provides tailored and holistic mental health support to 12 - 25 year olds. With a focus on early intervention, they work with young people to provide support at a crucial time in their lives – to help get them back on track and strengthen their ability to manage their mental health in the future.
Website: www.headspace.org.au

24 HOUR TELEPHONE COUNSELLING SERVICES

- **Kids Helpline**

Kids Helpline is a free 24/7, confidential and private counselling service specifically for children and young people aged 5 to 25 years. Counselling and support is provided via the phone, web and email. Children and young people have direct access to a counsellor and can choose to speak with either a male or female counsellor. They are also able to arrange to speak again with the same counsellor to work through their issues.
Telephone: 1800 55 1800
Website: www.kidshelpline.com.au

Appendix L: Emotion Thermometer



Emotion Thermometers 5 items

Instructions

In the first four columns, please mark the number (0-10) that best describes how much emotional upset you have been experiencing in the past week, including today. In the last column please indicate how much you need help for these concerns.

1. Distress 2. Anxiety 3. Depression 4. Anger 5. Need Help

Extreme

None

Desperately

Need to talk with someone

Can manage by myself

Alex J Mitchell © 2012

Appendix M: Attribution of published research outputs

Jenny Davies was the primary author of the four completed published manuscripts. The table below indicates what element of the manuscript each co-author contributed to.

Table 1. Author contributions to each published manuscript included in this thesis.

Manuscript 1: Parents' Experiences of Childhood Cancer During the COVID-19 Pandemic: An Australian Perspective

Co-Author	Concept & Design	Acquisition of Data & Method	Data Conditioning & Manipulation	Analysis & Statistical Method	Interpretation & Discussion
Jenny Davies	✓	✓	✓	✓	✓
Moira O'Connor	✓			✓	✓
Georgia KB Halkett	✓			✓	✓
Lauren Kelada	✓				✓
Nicholas Gottardo	✓				✓

Manuscript 2. Fathers' Experiences of Childhood Cancer: A Phenomenological Qualitative Study

Co-Authors	Concept & Design	Acquisition of Data & Method	Data Conditioning & Manipulation	Analysis & Statistical Method	Interpretation & Discussion
Jenny Davies	✓	✓	✓	✓	✓
Moira O'Connor	✓			✓	✓
Georgia KB Halkett	✓			✓	✓
Lauren Kelada	✓				✓
Nicholas Gottardo	✓				✓

Manuscript 3. Torn in two': Experiences of mothers who Are pregnant when their child is diagnosed with cancer

Co-Authors	Concept & Design	Acquisition of Data & Method	Data Conditioning & Manipulation	Analysis & Statistical Method	Interpretation & Discussion

Jenny Davies	✓	✓	✓	✓	✓
Moira O’Connor	✓			✓	✓
Georgia KB Halkett	✓			✓	✓
Lauren Kelada	✓				✓
Nicholas Gottardo	✓				✓

Manuscript 4. Grandparents’ Experiences of Childhood Cancer: A Qualitative Study

Co-Authors	**Concept & Design**	**Acquisition of Data & Method**	**Data Conditioning & Manipulation**	**Analysis & Statistical Method**	**Interpretation & Discussion**
Jenny Davies	✓	✓	✓	✓	✓
Moira O’Connor	✓			✓	✓
Georgia KB Halkett	✓			✓	✓
Lauren Kelada	✓				✓
Nicholas Gottardo	✓				✓

Co-Author acknowledgement:

I acknowledge that the contributions indicated in Table 1 represent my contribution to the research output and I have approved the final version.

Co-Author	**Signature**
Jenny Davies	
Moira O'Connor	
Georgia KB Halkett	
Lauren Kelada	
Nicholas Gottardo	

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Sock it to Sarcoma

Spark of Gold

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The Other C

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Children’s Hospital closed Facebook Support groups.

- Western Australia
- Tasmania
- South Australia
- Queensland
- New South Wales
- Victoria

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