School of Population Health

Discipline of Psychology

Faculty of Health Sciences

"I worry about Mum dying"

Children and their parents' cancer diagnosis

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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 (EC00262), Approval Number 2019-0808.

Signature: ………………….

Date: 27th of July 2022

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DEDICATION

~ I dedicate this thesis to my sister Zoe, whose short but tremendous fight against childhood cancer continues to inspire all that I am and do ~

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ABSTRACT

Background

There is increasing momentum in psycho-oncological research and healthcare practice, toward supporting cancer patients' young, minor children who are vulnerable to psychosocial and behavioural issues including somatic complaints, separation anxiety, distress, and worry, alongside potential long-term problems such as self-injury and post-traumatic stress symptoms. Yet, parents are unsure how to support children's coping and adjustment to their diagnosis, health professionals are reluctant to intervene, and there are limited interventions available to support children. Studies indicate factors such as family functioning, age and developmental stage, and parent-child communication may influence how children are affected by the diagnosis. However, there remains a paucity of literature regarding the impact of parental cancer on children and, as such, no consensus about the underlying mechanisms involved which determine how children are affected. Therefore, an in-depth exploration of how children are affected by their parent's diagnosis, including the underlying mechanisms which influence how children are affected, was warranted.

Aims

The overall aim of this study was to explore how children are affected by their parents' cancer diagnosis. Based on the findings from a systematic review which formed the preliminary stages of this study, a further objective of this study was to develop an explanatory model conceptualising the underlying mechanisms involved, which govern how children are affected by their parents' cancer diagnosis. The model was based on the comprehensive exploration of key informants' perspectives and was guided by relevant theoretical frameworks of symbolic interactionism and ecological systems theory. The specific aims for the systematic review and qualitative interviews with key informants were as follows:

Systematic review

The overall aim of the first study was to conduct a systematic review of the literature to identify and review the current interventions available for cancer patients' children and determine their effectiveness among children.

Qualitative interviews with key informants

The overall aim of this study was to explore how children are affected by their parents' cancer diagnosis, from the perspectives of children, parents, and health professionals and develop an explanatory model conceptualising the underlying mechanisms involved which influence how children are affected by their parents' cancer diagnosis.

Method

An integrated theoretical approach combining symbolic interactionism and ecological systems theory underpinned the present study. This approach considers the social interactions that influence children when their parent is diagnosed with cancer and the complex social forces which these relationships are embedded within. The overarching study comprising this thesis consisted of four studies. The initial study involved (1) a systematic review of the current interventions available for cancer patients' children. The findings of this review then informed the direction of the proceeding study, which developed a model conceptualising how children are affected by their parents' diagnosis. This was achieved by the three subsequent studies exploring (2) oncology health professionals' perspectives regarding how children are affected by their parents' cancer diagnosis, (3) parents (including patients and partners of patients) perspectives regarding how their ability to support their children is affected when a parent is diagnosed with cancer, and (4) children's perspectives regarding how they are affected by their parents' cancer diagnosis.

Study 1: Systematic review. The systematic review investigated the available interventions for patients' children. This was conducted using a broad search strategy to identify relevant references meeting the initial inclusion criteria proposed. Search words and strings included (children, youth, offspring) AND (parental cancer, breast cancer) AND (psychosocial, wellbeing, intervention). Mesh terms included: child of

impaired parents, neoplasms, prostate cancer, and palliative care. Seven databases and grey literature were systematically searched. This review was informed by the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines and Cochrane guidelines. Studies were appraised using a quality appraisal tool by Keim-Malpass and colleagues.

Studies 2, 3, and 4: Qualitative interviews with key informants. The three qualitative studies which explored key informants' perspectives of the effect a parent's cancer diagnosis has on their children were conducted using methods of constructivist grounded theory embedded within a social constructionist framework. A total of 38 participants, which included 15 oncology health professionals, 11 parents (including patients and partners of patients), and 12 children (5 to 17 years), were recruited using theoretical sampling methods. Recruitment primarily occurred through a Comprehensive Cancer Centre at a metropolitan tertiary teaching hospital. Children were recruited through participating parents. Semi-structured, in-depth interviews were conducted with key informants. Child interviews were assisted by a novel approach derived from play and art based developmental literature. Methods of constant comparison were used to analyse transcribed interviews.

Findings

Study 1: Systematic review. This review identified and analysed eight studies evaluating six psychosocial interventions designed to support cancer patients' children. The quality of interventions and evaluation studies were generally low and methodologically poor. Consequently, there were a limited number of significant results reported for children's self-reported outcomes. Post-Traumatic Stress Disorder symptoms, emotional regulation, and depression appear most amenable to current interventions, however, results were difficult to interpret due to poor study quality. Overall, current interventions were not effective among patients' children, highlighting the need for a theoretical model conceptualising how children are affected by their parents' cancer diagnosis.

Study 2: Health professionals. According to health professionals, when a parent is diagnosed with cancer, there were barriers in the (i) clinical healthcare system, and (ii) family's psychosocial context which made it difficult for health

professionals to identify patients' children and provide support, including referring them on to appropriate clinical or community services. Consequently, children were invisible to health professionals and, as such, did not receive timely support to help them cope with and adjust to, their parents' diagnosis.

Study 3: Parents. According to parents (including patients and partners of patients) there were practical factors associated with the cancer diagnosis centred around (i) adjusting to the cancer diagnosis, (ii) keeping life going, (iii) supporting the patient's physical and cognitive changes, and (iv) balancing parenting workloads and identities. The presence of these burdensome aspects of a cancer diagnosis and treatment meant parents were physically and mentally overwhelmed and consequently children's needs were often left unattended.

Study 4: Children. According to children, they were constantly (i) worried and distressed when their parent was diagnosed with cancer and there were barriers that exacerbated these feelings. These barriers focused on (ii) comprehending their parents' cancer diagnosis, (iii) being disconnected from their supports, and (iv) needing someone to talk to.

Conclusion

Findings from the systematic review indicate current interventions are not effective among patients' children, due to poor study quality, including the absence of a relevant theory or model to guide intervention research. As such, the recommendations from this review included the development of an explanatory model conceptualising how children are affected by their parents' diagnosis. Subsequently, the proceeding qualitative study following this review used methods of grounded theory to explore key informants' perspectives regarding how children are affected by their parents' cancer diagnosis, to develop a model. Findings from interviews with health professionals, parents/patients, and children informed the development of the Alexander's Children's Cancer Communication (ACCC) model for children with a parent with cancer. This model describes the underlying mechanisms involved that contribute to patients' children being *'not seen and not heard'* when their parent is diagnosed with cancer. Central to this model is the breakdown of fundamental interactions and communication processes between children and parents, and children and health professionals. Consequent of this, children were left to cope with their parents’ diagnosis alone, and this exacerbated their worry and distress. This study addresses the observed paucity of research in current parental cancer literature by providing an in-depth insight regarding children’s experiences when a parent is diagnosed with cancer, including how they are affected by the diagnosis and treatment. The ACCC model proposed can be used to inform future intervention development and evaluation thus improving the study quality and rigor of intervention research. Findings from this study have also been used to propose a series of recommendations to inform future clinical practice and healthcare research, which may be used to promote holistic psycho-oncological care for cancer patients and ensure their children are not left alone to cope with their parents’ diagnosis.

OVERVIEW OF THESIS

Chapter 1: Literature Review

Chapter One provides a general overview of the parental cancer literature. How families, parents, and children are affected by a parent's cancer diagnosis is discussed, and the context of clinical care and interventions that are available to support patients' children, are reviewed. As such, gaps within the research literature and clinical settings are identified, providing direction for future research studies. Informed by this review of the literature, this chapter concludes with the proposal for the need to conduct a systematic review of the current interventions available for cancer patients' children and their effectiveness, additional to the research aims, objectives, and questions.

Chapter 2: Study 1

Chapter Two consists of a published systematic review of the current empirically evaluated interventions available to support cancer patients' children and investigates the effectiveness of these interventions. The findings of this review highlight the lack of methodological rigor and ineffectiveness evidenced across interventions, which are then used to inform the direction of the overarching qualitative research study comprising this thesis. A rationale for adopting a grounded theory approach to explore how children are affected by their parents' cancer diagnosis from the perspectives of health professionals, parents, and children, is presented. The overall research aims, objectives, and questions are also presented. This chapter concludes by reporting the research significance of this study.

Chapter 3: Methodology

Chapter Three presents the methodological approach which underlies this study. The epistemological position of this study is outlined, followed by the theoretical framework which provides a research lens for exploring how children are affected by their parents' cancer diagnosis. Following this, a detailed account of constructivist grounded theory is discussed as the research methodology driving this study. A discussion of the methods and procedures used in this study are provided, which are again reported on in chapters 4, 5, and 6. These chapters consist of the individual studies comprising the overarching qualitative research study of this thesis. This chapter concludes with a personal reflexive piece by the researcher.

Chapter 4: Study 2

Chapter Four presents the published findings from study 2, which involved qualitative interviews with oncology health professionals exploring their perceptions of how patients' children are affected by their parents' cancer diagnosis. This study highlights the clinical and psychosocial barriers which contribute to patients' children being invisible to health professionals, consequently rendering children undetected and unsupported during their parent's cancer diagnosis. Directions for future research and clinical practice are also presented.

Chapter 5: Study 3

Chapter Five presents the findings from study 3, which involved qualitative interviews with parents (including patients and partners of patients) exploring how parents' ability to support their children is affected when a parent is diagnosed with cancer. This chapter reports on parents' sense of being overwhelmed by the practical and more burdensome challenges associated with the cancer diagnosis and how this contributes to them being unable to tend to children's needs. Directions for future research and clinical implications are also presented.

Chapter 6: Study 4

Chapter Six presents the findings from study 4, which used qualitative interviews assisted by a novel interviewing approach based on play and arts techniques, to explore children's perspectives of how they are affected by their parents' cancer diagnosis. The findings from this study emphasise children's worries and distress when a parent is diagnosed with cancer and their perceptions of being alone and disconnected from their social supports. Directions for future research and clinical implications are also presented.

Chapter 7: Discussion

Chapter Seven presents the discussion of this thesis by describing the underlying mechanisms involved when a parent is diagnosed with cancer, from the perspectives of health professionals, parents (including patients and partners of patients), and children. How these mechanisms contribute to the overarching theme, children are '*not seen and not heard'*, are discussed through the lens of the theoretical framework which underpins this study. An explanative model is proposed, which provides a conceptual understanding of the effect a parent's cancer diagnosis has on their children. The research implications for these findings, including the model, are discussed and clinical recommendations are provided.

CHAPTER 1 Introduction

Chapter Overview

This chapter introduces the thesis topic by providing an overview of the parental cancer literature and sets the scene for subsequent chapters. A detailed discussion of the current context that encapsulates the experiences of patients' children when a parent is diagnosed with cancer is provided, by detailing how families, parents, and children are affected by the diagnosis and subsequent treatments. Factors pertaining to family functioning, developmental considerations, and communication are also discussed, referent to how these contribute to children's ability to cope with and adjust to their parents' diagnosis. Clinical aspects focusing on healthcare professionals' provision of support for patients' children, in addition to the current interventions available to support children, are outlined. This chapter concludes with a rationale for the next steps in this study, a systematic review of the current interventions available for cancer patients' children, and the research aims, objectives, and questions posed to achieve this.

Prevalence

Children's experiences living with parental cancer is a growing area of research interest and clinical concern, however, there remains limited population data regarding the prevalence and characteristics of these children. Globally, the number of children living with a parent with a cancer diagnosis remains undetermined, though reports in the United States indicate approximately 2.85 million children aged 18 years and below were living with a parent with cancer in 2010 (Weaver et al., 2010). There are currently no Australian estimates available, though, a longitudinal study conducted in Western Australia (WA) reported 25, 901 (approximately 24%) children aged 0 to 11 years experienced a parent's cancer diagnosis between 1982 and 2015 (Martini et al., 2018). Furthermore, increasing five-year survival rates reported among Australian cancer patients aged 25 to 49 years (Australian Institute of Health and Welfare [AIHW], 2019), means patients and their families are living for longer with the impact of a cancer diagnosis (Werner-lin & Biank, 2009). These are considered child-rearing years, therefore, many of these patients will be challenged through supporting dependent children while also coping with their diagnosis (Syse et al., 2012; Weaver et al., 2010).

Families

Supporting the psychosocial needs of cancer patients involves considering their entire family, including children, because they too are impacted physically, psychologically, and emotionally by the ongoing demands of diagnosis and treatment (Faccio et al., 2018; Hauskov Graungaard, 2019; Walczak, 2018). Families with a parent who has been diagnosed with cancer face a unique set of challenges as they are likely to experience significant disruption to family dynamics and systems (Buchbinder et al., 2009; Semple & McCaughan, 2013; Visser et al., 2004). They may experience conflict regarding role changes, restrictions to daily life and activities, strains in marital and family relationships, and difficulties maintaining adequate social supports (Buchbinder, 2009; Helseth & Ulfsaet, 2003; Kim et al., 2006; Northouse et al., 2007). Other factors such as financial burden and the physical and emotional impact of treatment on the ill parent further exacerbate an already distressing and difficult time (Greening, 1992; Manne et al., 2007). These factors take a significant toll on parents, with one study indicating that increased illness demands were associated with poorer mental health among parents, which led to the deterioration of marriage quality and negative coping behaviours within the family (Lewis et al., 1993). Therefore, while parents endeavour to maintain normalcy, disruption is unavoidable and the family system is typically strained.

Parents

Parents are challenged to support their children's coping and adjustment and are concerned for their psychosocial wellbeing and development (Muriel et al., 2012). They are typically overwhelmed by aspects of the diagnosis, including reconciling their new roles as a patient or caregiver while simultaneously endeavouring to support children's needs (Semple & McCance, 2010; Thatsum et al., 2006). Prior research indicates parents who report higher levels of parenting concern are likely to experience greater psychological distress (Muriel et al., 2012), with the challenge of negotiating dual roles of caring for patients and children leading to more caregiving strain and greater emotional suffering compared to those without dependent children (Kim et al., 2006). Yet, children's health and functioning are closely tied to parents' wellbeing (Visser et al., 2004; Osborn, 2007), and tensions among conflicting demands means children's wellbeing is also likely to suffer alongside parents (Park et al., 2016; Rauch & Muriel, 2004). Parents are often distressed by the demands of the diagnosis including the taxation of the patient's symptoms or side effects of treatment, which renders them physically and emotionally unavailable to support children (Moore et al., 2015; Rauch & Muriel, 2004) and they are typically offered little help with these pressures. Consequently, children may be left alone to cope with their parents' cancer diagnosis and family changes, while attempting to remain on track developmentally (Huizinga et al., 2011; Semple & McCance, 2010; Turner et al., 2007).

Children

Cancer patients' minor (up to 18 years) children are confronted with a multitude of challenges across their parents' diagnosis and treatment. This can cause significant psychosocial distress for children (Gazendam-Donforio et al., 2009; Helseth & Ulfsaet, 2003; Kennedy & Llyod-Williams, 2009a; Patterson et al., 2016; Visser et al., 2004), particularly if parents are physically and emotionally unavailable to support them with their coping and adjustment to these challenges (Forrest et al., 2006). Consequently, their overall adjustment and emotional wellbeing is affected and they are vulnerable to developing various maladaptive psychosocial, emotional, and behavioural problems including somatic complaints, separation anxiety, distress, confusion, rumination, worry and intrusive thoughts (Morris et al., 2018; Walczak et al., 2018). While these outcomes are typically not experienced at a clinical level and are likely to dissipate over time, there is evidence indicating that some children remain vulnerable to long-term problems, including self-injury and post-traumatic stress symptoms (Bylund-Grenko et al., 2015; Lundberg et al., 2020; Stoppelbeing et al., 2006). In contrast, a small number of studies report the potential for positive outcomes among children, such as post-traumatic growth, strengthening of relationships, and resilience building (Greening, 1992; Helseth & Ulfsaet, 2003, 2005; Kennedy & Llyod-Williams, 2009a; Schmitt et al., 2008), while other studies report null or mixed findings (Jantzer et al., 2013; Lindqvist et al., 2007; Vannatta et al., 2008; Visser et al., 2007; Kuhne et al., 2012). As such, due to these conflicting findings, how children are affected by their parents' cancer diagnosis is unclear in the literature.

Existing research and methodological quality

Currently, the parental cancer literature remains limited and reported findings across studies are ambiguous and inconsistent (Faulkner & Davey, 2002; Visser et al., 2004), despite increasing concern and research interest for supporting patients' children (Faccio et al., 2018; Morris et al., 2019). Furthermore, the methodological quality observed across studies is generally poor, with issues including small sample sizes, no comparison groups, sampling bias, broad age ranges, and reliance on parent or teacher reports rather than children's self-reports (Faulkner & Davey, 2002; Huizinga et al., 2011; Su & Ryan-Wenger, 2007; Visser et al., 2004; Walczack et al., 2018). Though it is clear children's developmental outcomes are vulnerable to the impact of parental cancer, the specific psychosocial factors that are affected remain uncertain (Walczak et al., 2018). The most commonly assessed areas are those pertaining to psychological functioning, however, characterisation of this outcome (e.g., internalising and externalising symptoms, depression, anxiety etc.) varies considerably across studies making it difficult to interpret results (see review by Walczak et al., 2018). As such, consensus regarding how children are affected by their parents' cancer diagnosis and the mechanisms underlying children's potential outcomes, including their coping and adjustment, is yet to be determined. Factors related to family functioning appear to have the most predictive and supportive value regarding children's coping, however, results pertaining to other factors such as age, gender, and illness characteristics are less consistent (Walczak et al., 2018).

Family functioning

Children are embedded within their family system and rely on parents to address their physical, emotional, and psychological needs (Malin et al., 2016; Visser et al., 2006). However, a parent's cancer diagnosis brings significant disruption to family functioning which impacts children’s coping and adjustment (Babore et al., 2019; McDonald et al., 2016; Muriel et al., 2012; Visser et al., 2006). Evidence indicates poorer family functioning and related factors such as the wellbeing of family members, the family’s coping style, and parent-child attachment style and relationship, are predictive of children’s psychosocial outcomes (McDonald et al., 2016; Walczak et al., 2018; Lewis et al., 1993; Vannatta et al., 2010). Other factors such as parents’ marital functioning, the family structure (e.g., single or dual parents), and family communication style also influence children’s coping (Visser et al., 2006). Families of out-patients are particularly challenged to support children, as both children and parents are unable to escape the burden of the disease, including ongoing exposure to treatment side effects which can prove distressing and confronting for them (Christ et al., 1993; Zahlis, 2001). Family support and time out from the cancer daignosis are key needs reported by children, particularly those bereaved by parental cancer (Maynard et al., 2013; Patterson et al., 2016). Higher levels of unmet needs among children are likely to lead to their increased distress (Patterson et al., 2017; McDonald et al., 2016), yet meeting these needs is challenging for families who are struggling to cope. Moreover, children’s needs vary with age and for families with multiple children it is difficult to support the needs of their children who are at various developmental stages.

Developmental considerations

Children typically lack the emotional and cognitive maturity to understand their parents’ cancer diagnosis, and this often leads them to harbouring erroneous and maladaptive thoughts (Bugge et al., 2008; Christ, 1993). Egocentric thinking can mislead children to assuming they are the direct cause of their parents’ diagnosis (Christ et al., 1993; Biank & Werner-lin, 2011) and a determinant of their parents’ ongoing health (Helseth & Ulfsaet, 2003). In the absence of intervention, these erroneous thoughts can lead to heightened levels of fear, anxiety, and rumination that render children physically and emotionally debilitated (Bugge et al., 2008; Christ et al., 1993). Without sufficient communication and information provision, children are likely to make sense of their parents’ diagnosis through magical thinking and by integrating other knowledge and experiences, such a media, friends, and school (Biank & Werner-lin, 2011; Forrest et al., 2006). However, this may prove detrimental with children forming illogical and misinformed conclusions that result in unnecessary worry, for example *‘I wondered if it would end up the same as what happened with my grandma – if she* [mother with breast cancer] *would die”* (Zahlis, 2001, p. 1022). Open, timely, and age-appropriate communication mitigates the potential for children’s confusion or to harbour misconceptions about their parents’ cancer diagnosis and is considered integral to supporting children’s psychosocial wellbeing (Durant, 2012; Howell et al., 2016; Taylor-Brown et al., 1993; Wong et al., 2010).

Communication

Many parents are uncertain how to talk to children and children struggle to make sense of their complex thoughts and emotions. They are typically unable to articulate and express their concerns as they do not possess the required cognitive sophistication to do so (Beale et al., 2004; Christ, 1993; Helseth & Ulfsate, 2003; Kornreich et al., 2008). Consequently, parents often underestimate children’s level of need for information (Forest et al., 2006) and the burden of these thoughts and emotions may manifest as behavioural changes such as increased crying, separation anxiety, distractibility, and aggressive and deviant behaviour (Christ et al., 1993; Kornreich et al., 2008). Alternatively, some children avoid conversations with parents, finding it easier to mask their feelings or preferring to protect parents for fear of upsetting them, and (Bugge et al., 2008; Helseth & Ulfsaet, 2003; Kennedy & Lloyd-Williams, 2009b; Stiffler et al., 2008). Furthermore, there is evidence to suggest parents may not recognise when children are not coping and potentially overestimate children’s psychosocial functioning and adjustment to the cancer diagnosis (Kennedy & Lloyd-Williams, 2009a; Lewis et al., 2006; 2015) which may be due to inadequate communication. Children feel they need more information and communication about their parents’ diagnosis (Barnes et al., 2000; Fearnley & Boland, 2017; Kennedy & Lloyd-Williams, 2009b; Patterson et al., 2016), however, parents commonly report their apprehension for providing age-approariate communication and need for professional support with this (Dalton et al., 2019; Dencker et al., 2019; Sinclair et al., 2019).

Health professionals and clinical support

Health professionals in the patient's oncological treating team are well positioned to identify patients' children, however, they are often overwhelmed, and their primary focus is the patient (Helseth & Ulfsaet, 2003; Niemela et al., 2012), hence children are typically not on their radar (Arber & Ordelius, 2018; Niemela et al., 2012). Also, they are usually specialised in adult care and their experience and knowledge of children is limited (Dalton et al., 2019; Dencker et al., 2019; Huizinga et al., 2011). Parents commonly express their need for help from health professionals with supporting children and seeking clinical or therapeutic help (Dencker et al., 2019), however, barriers such as limited developmental knowledge and awareness of children render health professionals unable to provide this support and consequently this does not appear to be occurring (Baider, 1995; Dencker et al., 2019). While children indicate their preference to talk to parents about their cancer diagnosis (Phillips & Prezio, 2016), they also want input from health professionals, particularly regarding medical and specialist information (Barnes et al., 2000; Kennedy & Llyoyd Williams, 2009b; Fearnley & Boland, 2017). Yet, parents report waiting for health professioanls to broach the subject of children and health professionals tend to avoid the topic of children, thus exacerbating the unlikeliess of health professionals to detect or support children (Dencker et al., 2019). Furthermore, children do not consider hospitals as a place to seek emotional help (Finch & Gibson, 2009) and do not feel they can directly approach health professionals (Kennedy & Llyod-Williams, 2009b). There is also limited research regarding health professionals' perceptions of supporting cancer patients' children and their needs and challenges with providing this support. Health professionals would benefit from knowledge of how to support children and having access to empirical resources, including child-centred psychosocial interventions.

Interventions

There is a paucity of structured, child-centred interventions available to support children's psychosocial wellbeing when a parent is diagnosed with cancer (Ellis et al., 2017; Ohan et al., 2020; Walczak et al., 2018). Of those that do exist, most interventions are not developed based on a strong theoretical or conceptual basis or evaluated using a rigorous and transparent evaluation process, including poor recruitment methods, insufficient sample sizes, and the absence of valid, reliable, and developmentally appropriate measures (Ellis et al., 2017; Niemela et al., 2010; Ohan et al., 2020; Semple & McCaughan, 2013; Su & Ryan-Wenger, 2007; Walczak et al., 2018). Children are also seldomly included in the development process of interventions, and evaluation studies typically refer to parent proxy-reports rather than children's self-reports, which disregards the unique insight children offer (Bradbury-Jones et al., 2018). Moreover, reported discrepancies between parent proxy-reports and children's self-reports (Eiser & Morse, 2001; Huizinga et al., 2010; Jardine et al., 2014; Lewis et al., 2006; 2015) indicate children's perspectives are crucial to understanding intervention effectiveness. However, current reviews of interventions are yet to tease apart parent's and children's reports for child-related outcomes such as depression and anxiety, consequently making it difficult to apporpriately interpret results.

Findings from qualitative evaluation studies suggest there is a need for interventions to support patients' children, with participant feedback indicating interventions are well received and generally have a positive impact on subjectively reported psychosocial outcomes (Bugge et al., 2008; Davey et al., 2013; Landry-Dattee et al., 2016; Semple & McCaughan, 2013; Thatsum & Munch-Hansen, 2006; Tucker et al., 2013). However, conflicting results are reported across studies that have evaluated intervention effectiveness with quantitative outcome measures, which is likely due to observed methodological limitations and the high level of heterogeneity across outcome measures included across studies (Ellis et al. 2017; Niemela et al., 2010; Ohan et al., 2020; Walczak et al., 2018). Also, when interventions are effective, the mechanisms of change are typically not reported. Therefore, it is presently difficult to interpret the results pertaining to intervention effectiveness reported across studies, and to know what components of interventions are effective among cancer patients' children and why they are effective. Furthermore, a review by Ellis and colleagues (2017) indicated that the large proportion of qualitative studies included in their systematic review of current interventions, made it difficult to determine the efficacy of included interventions, suggesting the need for a more focused review of quantitative results to determine the potential efficacy of existing interventions for use in clinical practice.

Conclusion and directions for future research

When a parent is diagnosed with cancer, their children are vulnerable to various psychosocial, emotional, and behavioural problems, yet, despite parents' requests for clinical support, health professionals find it challenging to provide this assistance (Dalton et al., 2019; Dencker et al., 2019; Sinclair et al., 2019). Furthermore, there are few structured, child-centred interventions available to support children and intervention evaluation studies have not been conducted using methodologically robust approaches, which contributes to the lack of intervention effectiveness observed across studies (Ellis et al. 2017; Niemela et al., 2012; Ohan et al., 2020). When interventions are effective, the mechanisms for change are seldomly reported, hence it is unknown what is effective among children and why. Children are also rarely used in the development of interventions, and evaluation studies rely on parent proxy-reports over children's, which makes it difficult to determine how effective interventions are with supporting child-related outcomes, thus warrenting the need to examine intervention efficacy according to children. Also, previous reviews include qualitative, quantitative, and mixed-design studies, which challenges capacity for synthesising results and interpreting intervention effectiveness. As such, there was need for a full appraisal and systematic review of the effectiveness of current interventions. This review would elucidate what interventions are currently in place for cancer patients' children and the nature of these interventions, including the components comprising interventions which are effective and why they are effective, thereby, informing future directions for intervention research.

Research aims and objectives

The overall aim of the first study was to conduct a systematic review of the literature to identify and review the current interventions available for cancer patients' children and determine their effectiveness among children.

The specific objectives of the systematic review were to:

- Identify the current interventions available for cancer patients' children.
- Review the nature of these interventions.
- Determine how effective these interventions were at supporting patients' children.

Research questions

The research questions posed to achieve the research aim and objectives were:

- What are the interventions currently available to support children living with a parent with cancer?
- How effective are these for children?

CHAPTER 2 Study 1: A systematic review of the current interventions available to support children living with parental cancer[3]

Chapter Overview

This chapter consists of a systematic review of the current interventions available for patients' children and determines their effectiveness in supporting children when a parent is diagnosed with cancer. The purpose of this review was to systematically identify what is currently available for children, to establish the nature of interventions and whether they are effective in mitigating children's adverse outcomes. The findings of this review will inform the future direction of this study by evidencing what is needed in parental cancer research to support children's coping and adjustment to their parents' cancer diagnosis. This review has been published as a peer reviewed article, titled 'A systematic review of the current interventions available to support children living with parental cancer', in *Patient Education and Counseling*, an interdisciplinary journal for applied patient education, counselling, and health promotion research. The article provides a detailed analysis of the six interventions identified, including an evaluation of study quality, breakdown of the components comprising interventions, and their reported effectiveness among patients' children. As such, this review provided the necessary data which directed the focus of this study toward developing an explanative model conceptualising children's experiences when a parent is diagnosed with cancer. This chapter concludes with a detailed rationale for the proposed study, additional to the research aim, objectives, and questions.

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[3] This chapter has been published in the journal *Patient Education and Counseling* and can be found online here.

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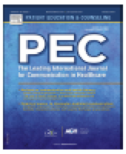

Review Article

A systematic review of the current interventions available to support children living with parental cancer

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ABSTRACT

Objective: Children living with parental cancer are vulnerable to distress and developmental disruption. This review aims to identify current interventions to support cancer patients' children and summarise how effective these are based on children's reports.
Methods: Between 25 May 2015 and 6 August 2018, a broad search strategy was used to identify relevant references. Seven databases were searched, and grey literature was also vetted. This review was informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and Cochrane guidelines.
Results: Eight studies evaluating six interventions were retained. Research designs and interventions were heterogenous, and study quality was low. A limited number of significant results were reported by studies. These evidenced improvement for PTSD symptoms, emotional regulation, and depression. However, overall current interventions do not appear effective among patients' children.
Conclusion: Despite encouraging preliminary findings, interventions do not yet adequately support cancer patients' children. There is a need for more tailored and targeted interventions. A theoretical model conceptualising the impact of parental cancer may assist this.
Practice implications: Findings will assist future intervention research by promoting standardised levels of care among cancer patients' children, that is empirically supported, effective, and meets principles of non-maleficence.

Contents

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1. Introduction

Young adults, aged 25–49 years, account for approximately 10% of new cancer cases [1]. The implications of a cancer diagnosis for this younger cohort, differ from older people with a cancer diagnosis as they are still likely to be in the workplace or studying, and many will have dependent children still living at home [2]. When a parent has cancer, their entire family deals with the impact of this chronic and often unpredictable stressor [3,4]. Families may experience conflict regarding changes to roles and responsibilities, restrictions to normal activities, strained marital and family relationships, and difficulties maintaining adequate social supports [5–7]. Other factors such as financial burden and the physical and emotional impact of treatment on the ill parent further exacerbate this [8,9]. The diagnosis of cancer in a parent presents an extremely taxing, disruptive and distressing time for the patient and their families.

Families with children face additional challenges, as patients' children attempt to cope with and adjust to their parent's cancer and family changes, while remaining on track developmentally [4]. There is evidence indicating that the overall adjustment and wellbeing of patients' children is likely to be affected, in addition to the establishment of various maladaptive psychosocial, emotional, and behavioural stress responses [4,10]. These include somatic complaints, separation anxiety, high levels of distress, confusion, rumination, worry and intrusive thoughts [11–14]. However, studies have also reported resilience and even the potential for post-traumatic growth among cancer patients' children [14–17]. Childrens' response is also subject to fluctuations over time, and dependant on variables such as age, gender, illness stage, pre-existing comorbidities, marital status, and parents' psychological health [10,12,17]. Therefore, the research regarding how children are affected by their parent's cancer requires further investigation [4].

Oncology health professionals (HPs) are customarily overwhelmed, and often their primary focus is the patient. HPs in adult settings are usually specialised in adult care, therefore their expertise and experience with children is limited, rendering staff insufficiently skilled to support patients' children [4,18]. Consequently, the needs of patients' children are typically not addressed [18–20]. Yet, for parents, the impact of their cancer on their dependent children is a constant source of concern [21] and information provision of interventions is absent from routine care [22]. There also remains a shortage of published and empirically supported interventions available for application in clinical settings [18,23]. Further research is necessary to both identify and support children at risk or in need [4]. More empirically supported, tailored interventions that consider individual and cohort differences such as age, gender, cultural identity, pre-existing morbidity (children and parents) and stage of disease, are required.

Persevering concern for the detrimental impact a parent's cancer diagnosis and treatment presents to their vulnerable and developing child, has led to renewed interest in this area of research. Reviews thus far indicate that at a qualitative level, interventions seem promising, and are well received [18,23]. The qualitative literature appears consistent, with several themes emerging across studies capturing participants' experiences with interventions, such as improved isolation and normalisation [22,23]. Alternatively, quantitative evaluation regarding intervention efficacy remains to be adequately unpacked and group impact yet to be sufficiently determined [23]. Of the limited number of quantitative studies available, interventions appear insufficient at effectively attenuating proposed psychological and behavioural concerns among patients' children [23–26]. However, results remain ambiguous and inconsistent across studies, therefore necessitating further investigation into the efficacy of current interventions regarding children's psychological outcomes.

Research has also highlighted considerable discrepancies often reported between children's self-reports and parent's proxy reports [12,25–28], thus signifying a possible disconnection within this relationship, or for parent proxy-reports to confound perceptions of their children's functioning [25]. With growing recognition for children's capacity to effectively report on their own psychological and behavioural consequence, we intend to retain only studies that have included children's self-report measures. While previous reviews have allowed scope for evaluation studies that relied solely on proxy-reports, to influence outcomes [3,18,23], we feel that the child's self-perspective is crucial to informing the decision-making process, as it may provide information that is unattainable through alternative sources [27,29–31].

1.1. Aims

This review will seek to address the following research questions, (i) what are the interventions currently available to support children living with a parent with cancer, and (ii) how effective are these among children?

2. Method

This review complies with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [32] and Cochrane guidelines [33]. A PICO (population, intervention, comparison, outcomes, study type) approach to inclusion criteria was used for this review (see Table 1).

2.1. Search strategy

Between 25 May 2015 and 6 August 2018, a broad search strategy was employed to identify references pertaining to the research question. Search words and strings included (children, youth, offspring) AND (parental cancer, breast cancer) AND (psychosocial, wellbeing, intervention). Mesh terms included child of impaired parents, neoplasms, prostate cancer, and palliative care. The inclusion of the terms *breast cancer, prostate cancer* and *palliative* were included to broaden our search. A general search of the literature informed us that these areas of research are common in the parental cancer literature, possibly due to the high prevalence of these cancers among patients who are of typical parenting age. No limits were applied to the initial search. Databases searched were: Medline, PsycInfo, ProQuest, Cochrane, CINAHL, Embase and Google Scholar. To minimise the possible biased reporting of results [33,34], grey literature searches were also conducted in Google, ProQuest conferences and Proquest theses. Hand-searched journals included *Journal of Psychosocial Oncology, Psycho-oncology* and *Cancer*. The reference lists of identified studies were also searched.

2.2. Screening

The initial search resulted in 3322 references. Duplicates, studies published prior to 2006 (<12 years), books, reviews, and

Table 1
PICO Definitions of Inclusion Criteria.

PICO	Inclusion criteria
Population	Children living with parental cancer aged 18 years and below
Intervention	Any psychosocial intervention that supports patients' children's psychological, emotional and behavioural issues
Comparison	Care as usual or no care
Outcomes	Change or no change reported
Study type	Quantitative or mixed methods

non-English papers were checked for and removed (see Fig. 1). Grey literature was also vetted, however, was deemed not to add enough value to merit inclusion in this review [33]. Titles and abstracts were screened for relevance. Where relevance could not be ascertained, the full text was located. The first 4 papers (alphabetically) were independently piloted by two raters (E.A., N. R.) using the original pre-determined PICO criteria (see Table 1). To reduce ambiguity and promote inter-rater reliability, any suggested changes were discussed. Minor changes were made, resulting in the following criteria:

Includes children and adolescents aged 18 years and below

- Children have a parent with cancer
- Parent has a primary diagnosis of any type of cancer, at any stage
- Participants are from any type of settings including community, hospital or residential
- Patients' children are the significant focus of the study
- Explores issues, including psychological, developmental and behavioural issues with regards to patients' children
- Empirically evaluates any psychological intervention that addresses these issues
- Reported degree of change, or no change, in outcome variables are reported by children and adolescents with a parent with cancer
- Uses any type of quantitative outcome measure

Autonomous application of the criteria to the entire set was then directed by the same two raters. Papers that received different review scores, were discussed and a final review score was determined. Papers that did not meet these criteria were discarded.

2.3. Data extraction and analysis

Data were extracted into standardised forms by one researcher (EA), and included: study design, aim, sample, location; intervention description, intensity; measures and outcomes; key results/findings and effect sizes; and efficacy and feasibility. Due to the high level of heterogeneity across the research designs of included studies and the diversity of interventions, results were combined using techniques of narrative synthesis [35,36].

2.4. Quality assessment

An appraisal tool, developed by Keim-Malpass and colleagues [37] (see Table 2), was used to assign a quality rating to each of the papers to further aid interpretation (see Table 3). For mixed design studies, only the quantitative component of the study was assessed. According to the developers, this tool is appropriate for a heterogenous sample, as it does not penalise based on study design. This tool appraises studies based on their consistency, generalisability, and overall impact the study yields on the systematic review [37]. Each study is assigned a number indicating study design, and 'A', 'B' or 'C', to indicate study quality (high, good, low - respectively). A study with a low-quality ranking does not necessarily indicate the study was poorly conducted, rather it

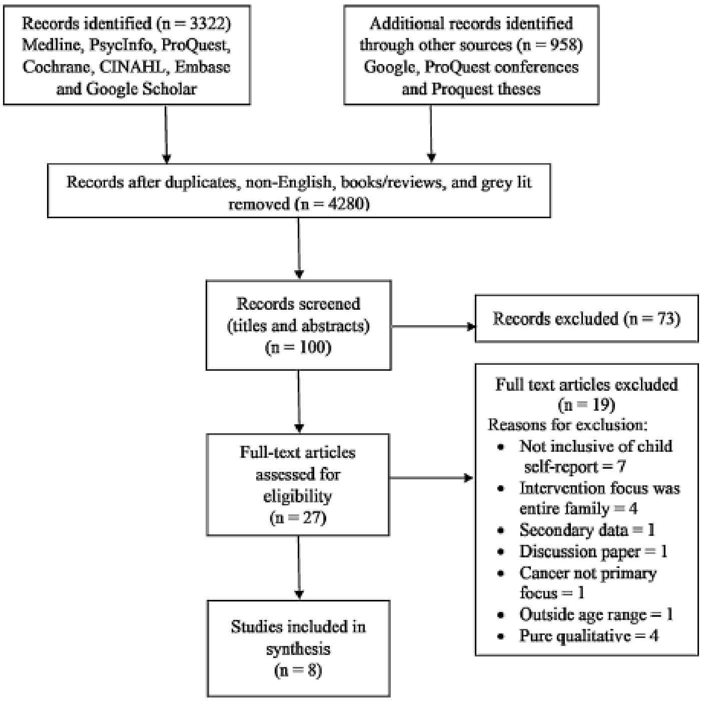

Fig. 1. PRISMA flow diagram, PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

infers the limited scope for the findings of that study to aid with overall interpretations for the present systematic review [37]. The quality ranking assigned to each study is presented in Table 3, in order of highest-ranking study to lowest-. These rankings should be used to aid interpretation and contextualise our reported results and findings.

3. Results

The final set retained for analysis included 8 studies that evaluated 6 interventions (see Fig. 1).

The characteristic features of interventions are summarised in Table 4. Interventions comprised a mix of content and delivery formats. Individual or group-based counselling (n = 3) [24–26,38] and manualised programs (n = 2) [39,40] were the most common forms of delivery. Intervention intensity also varied across and within interventions. The shortest was a single 3-h long session [39] and the longest comprised 5–6 sessions across an unspecified time [24]. Delivery of most interventions was generally flexible and individually adapted based on participants needs. Interventions were typically facilitated by a trained professional with a health care background; and most were provided at home or in a clinical setting such as a hospital. Four interventions were guided by theory [24–26,39,40]. Objectives were varied, with intervention aims including; improving emotional functioning, adjustment, and QoL among children and parents [25,26,39,41,42], facilitating communication and engagement with support networks [40–42], strengthening parent-child attachment [40], and enhancing parenting behavior [24]. Core components comprising interventions also appeared similar across the set. The most prevalent being communication enhancement (n = 5) [24–26,38,40–42] and supportive counselling (n = 5) [24–26,39,41,42].

There was a high level of heterogeneity across study research designs. The key features of studies are summarised in Table 5. Only the quantitative components of the mixed methods studies have been presented [24,25,40]. Issues with control, standardisation, incorporation of theory, and reporting quality were prevalent across all studies, including randomised controlled trials (RCT). Recruitment challenges predominantly influenced the capacity for randomised sampling and assignment to groups (control and experimental). Of the 3 studies that reported attrition, reasons for this included time constraints, program feasibility and challenges to participants' health, including death of the ill parent [24,26,39]. Just 2 studies reported power analyses, and both were underpowered at post-intervention intervals [26,39]. Program fidelity and methods for monitoring this were reported by 5 studies [25,26,40–42].

Table 2
Keim-Malpass and Colleagues (2015).

Rating number (design)	Details
LEVEL I	Randomised control trial (RCT) or experimental study
LEVEL II	Quasi-experimental (no manipulation of independent variable, may have random assignment or control)
LEVEL III	Non-experimental (no manipulation of independent variable, includes descriptive, comparative, correlational studies or uses secondary data)
LEVEL IV	Qualitative (focus groups, starting point where no previous data exists).
X	Study did not meet final inclusion criteria
Rating rank (quality)	**Details**
A – HIGH	Consistent, generalisable results, sufficient sample size, adequate control, definitive conclusions, consistent recommendations based on comprehensive literature review that includes thorough reference to scientific evidence
B – GOOD	Reasonably consistent results, sufficient sample size for the study design, some control, fairly definitive conclusions, reasonably consistent recommendations based on fairly comprehensive literature review that includes some reference to scientific evidence
C – LOW	Little evidence with inconsistent results, insufficient sample size for the study design, conclusions cannot be drawn

Note. Tool Adaptation with Permission from the Association of Perioperative Registered Nurses (AORN).

Table 3
Quality Rating for Included Studies.

First author and year	Study type	Rating (design)	Rating (quality)	Overall quality rating
Lewis et al. (2015)	Quant	I	A/B	I, A/B
Hauken et al. (2017)	Quant	I	A/B	I, A/B
Kobayashi et al. (2017)	Quant	II	B	II, B
Davey et al. (2013)	Mixed	II	B	II, B
Thatsum et al. (2006)	Mixed	II	B	II, B
Shallcross et al. (2016)	Quant	II	B	II, B
Azarbarzin et al. (2015)	Quant	II	C	II, C
Lewis et al. (2006)	Mixed	III	B	III, B

The methodologically strongest evidence came from a Norwegian multisite, RCT by Hauken et al. [39], which received a quality rating I, A/B. In this study, the authors evaluated the *Cancer PEPSONE Program* (CPP, see [43] for research protocol), a theory-based, manualised, psychoeducation program aimed at optimising families' social support networks to promote Quality of Life (QoL). This was compared to a randomised control group ($n = 17$) who received psychoeducation and social support as usual. Power analyses indicated diminished study power at T2 and T3 post-intervention. Reasons cited include relapse or death of ill parent, and illness of healthy parent or child. No significant differences were reported for overall QoL by children using the Kinder Lebensqualitat (KINDL) or anxiety using the Revised Children Manifest Anxiety Scale (RCMAS). However, significant improvement by group was evidenced for the family functioning subscale ($n = 35$, $p = 0.018$, Cohen's $d = 0.86$) on the KINDL, with a large effect size.

A multisite RCT that was conducted in the USA by Lewis et al. [26] also received a methodological quality rating of I, A/B. This study evaluated *The Enhancing Connections Program* (TECP) [25,26], an intensive, theory-based, scripted psychoeducation and supportive counselling program in addition to take home workbooks, for mothers with breast cancer and their children. Compared to a sample of randomised controls who received psychoeducation via a mailed booklet and phone call, the authors evidenced significant improvement to levels of depression as reported by children at 12 months post-intervention ($n = 123$, $p = 0.025$, Cohen's $d = 0.34$), using the Child Depression Inventory (CDI). No other significant results were found among children. Power analyses indicate diminished study power at 2- and 12-months post-intervention. Reasons for attrition included lost to follow-up, preference for an alternative program, did not want/need, and too busy.

A recent study by Kobayashi et al. [41] that received a quality rating of II, B, evaluated a culturally adapted version of *Children's Lives Include Moments of Bravery* (CLIMB) among Japanese children and their parents using a quasi-experimental, within-subject design. Here, the authors' reported significant improvements to children's Posttraumatic Stress Disorder (PTSD) symptoms on The Posttraumatic Stress Disorder-Reaction Index (PTSD-RI, $p = 0.010$), particularly on items regarding children's self-blaming and

Table 4
Summary of Intervention Characteristics and Components.

Intervention Study(s)	Intervention theory	Intervention aim	Participants	Frequency	Intervention content	Components							
						A	B	C	D	E	F	G	H
The Enhancing Connection Program **Lewis 2015 ;Lewis 2006**	Developmental-contextual model of parenting; Coping theory; Social cognitive theory	Improve mother's emotional functioning, strengthen parenting behaviour and improve children's adjustment	Mother & child	10 weeks 5 fortnightly sessions 60 mins p/ses.	Scripted patient (mother) education counselling ses. Interactive workbook Children's activity booklet Phone access to educator	✓	✓	✓			✓		
A Supportive-educative program **Azarbarzin et al. (2015)**	No theory	Improve child's QoL.	Adolescents with a parent with cancer	45-90 mins p/ses. (depending on needs)	Individual/group information and counselling sessions Booklet, compact disk and weblog access at end of program	✓	✓						
A culturally adapted program **Davey et al. (2013)**	Attachment theory	Improve family communication and parent-child attachment	Family	10 weeks (twice p/mnth) 2 phases: *Phase 1*- 3 × 90-minute child support group sessions. *Phase 2*- 2 × 2-h multiple group family sessions.	Manualised treatment program		✓	✓	✓	✓	✓	✓	✓
Children's Lives Include Moments of Bravery (CLIMB) **Kobayashi et al. (2017) ; Shallcross et al. (2016)**	No theory	Provide information, normalise emotions improve communication and strengthen connections among children.	Children with a parent with cancer	6 weeks 1.5 to 2 hrs weekly group meetings	Group based, art and play activities for children	✓	✓	✓			✓		
Children of Somatically Ill Parents (COSIP) Multinational **Thatsum & Munch-Hansen (2006)**	Family therapy	Primary goal was to support the family in taking care of the children's needs as best as possible.	Family	Average 4.7 mths Max. of 5-6 ses.	Preventative counselling sessions with whole family. Children also offered group sessions		✓	✓			✓		
Cancer PEPSONE Program (CPP) **Hauken et al. (2017)**	Quality of life theory Learning theory	Investigate intervention effects on children's anxiety and QoL.	Family	1 session, 3 hours long	Manual-based	✓					✓		✓
					Total	4	5	4	1	1	5	1	2

Note *(A) Psycho-education; (B) Supportive counselling/express feelings; (C) Build Coping Skills; (D) Mood Monitoring; (E) Relaxation Exercises; (F) Enhance Communication; (G) Pleasant Event Scheduling; (H) Enhance Social Support.

egocentric thinking. No other effects were found for children's psychosocial stress.

Davey et al. [40] conducted another culturally modified study among African-American participants and received a quality rating of II, B. In this study, the authors compared a manualised psychoeducation and supportive counselling intervention designed to enhance communication, to a non-randomised control group receiving psychoeducation as usual. While a medium effect size was reported for communication among intervention children (Cohen's $d = 0.72$), no other significant improvements were detected on other symptoms of children's psychological distress, excluding their program satisfaction ($p = .006$, Cohen's $d = 1.58$).

An earlier pilot study of the CLIMB program that was conducted in America by Shallcross et al. [42] across five sites, received a quality ranking of II, B. Within-subjects analysis evidenced significant improvement to children's emotional regulation ($p < 0.05$, Cohen's $d = 0.57$), on the dimensions of awareness ($p < 0.05$, Cohen's $d = 0.66$) and suppression ($p < 0.01$, Cohen's $d = 0.85$) with medium to large effect sizes. An earlier multisite, German study by Thatsum et al. [24], which also received a quality rating of II, B reported on the short-term impact of a multinational, supportive counselling, and coping skills enhancement program- *Children of Somatically-Ill Parents* (COSIP). Using the Beck's Youth Inventories (BYI), the authors' evidenced a significant improvement to children's depression ($p < .01$).

The initial pilot study by Lewis et al. [25] which evaluated *The Enhancing Connections Program* (TECP), received a quality rating of III, B due to its limited sample size. This study reported conflicting results to their later RCT [26], with no significance detected for children's depression as reported by the CDI. However, the authors did report significant improvement to children's cancer related worries ($p = 0.04$) on the Cancer Worries Scale. Another methodologically poorer study by Azarbarzin et al. [38] received a quality rating of II, C due to documented evidence of insufficient study control and limited reporting quality. Here, significant results on aspects of QoL among an Iranian sample of adolescents who engaged in a supportive educative program, were found.

4. Discussion and conclusion

4.1. Discussion

This review addressed the research questions, (i) what are the interventions currently available to support children living with a parent with cancer, and (ii) how effective are these among children?

A comprehensive literature search identified just eight studies evaluating six interventions that both supported patients' children and engaged children in the evaluation process. A small number considering the pervasiveness of this concern [44] and when compared with similar areas of research. For example, a review by

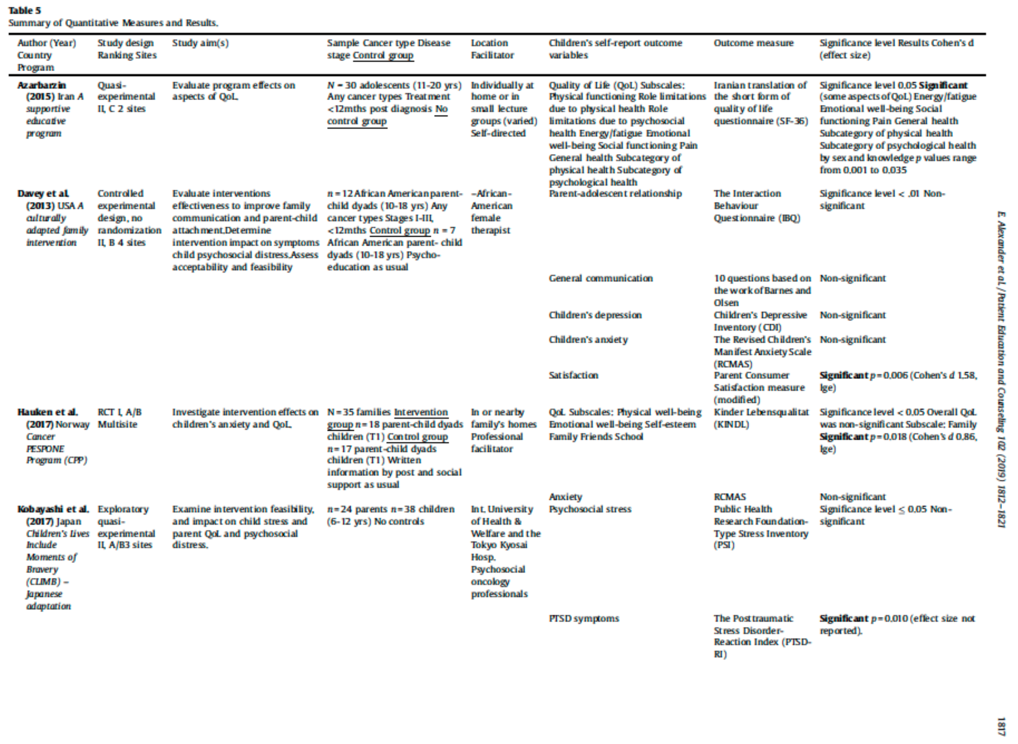

Table 5
Summary of Quantitative Measures and Results.

Author (Year) Country Program	Study design Ranking Sites	Study aim(s)	Sample Cancer type Disease stage Control group	Location Facilitator	Children's self-report outcome variables	Outcome measure	Significance level Results Cohen's d (effect size)
Azarbarzin (2015) Iran *A supportive educative program*	Quasi-experimental II, C 2 sites	Evaluate program effects on aspects of QoL.	$N = 30$ adolescents (11-20 yrs) Any cancer types Treatment <12mths post diagnosis No control group	Individually at home or in small lecture groups (varied) Self-directed	Quality of Life (QoL) Subscales: Physical functioning Role limitations due to physical health Role limitations due to psychosocial health Energy/fatigue Emotional well-being Social functioning Pain General health Subcategory of physical health Subcategory of psychological health	Iranian translation of the short form of quality of life questionnaire (SF-36)	Significance level 0.05 **Significant** (some aspects of QoL) Energy/fatigue Emotional well-being Social functioning Pain General health Subcategory of physical health Subcategory of psychological health by sex and knowledge p values range from 0.001 to 0.035
Davey et al. (2013) USA *A culturally adapted family intervention*	Controlled experimental design, no randomization II, B 4 sites	Evaluate interventions effectiveness to improve family communication and parent-child attachment.Determine intervention impact on symptoms child psychosocial distress.Assess acceptability and feasibility	$n = 12$ African American parent-child dyads (10-18 yrs) Any cancer types Stages I-III, <12mths Control group $n = 7$ African American parent- child dyads (10-18 yrs) Psycho-education as usual	–African-American female therapist	Parent-adolescent relationship	The Interaction Behaviour Questionnaire (IBQ)	Significance level < .01 Non-significant
					General communication	10 questions based on the work of Barnes and Olsen	Non-significant
					Children's depression	Children's Depressive Inventory (CDI)	Non-significant
					Children's anxiety	The Revised Children's Manifest Anxiety Scale (RCMAS)	Non-significant
					Satisfaction	Parent Consumer Satisfaction measure (modified)	**Significant** $p = 0.006$ (Cohen's d 1.58, lge)
Hauken et al. (2017) Norway *Cancer PESPONE Program (CPP)*	RCT I, A/B Multisite	Investigate intervention effects on children's anxiety and QoL.	N = 35 families Intervention group $n = 18$ parent-child dyads children (T1) Control group $n = 17$ parent-child dyads children (T1) Written information by post and social support as usual	In or nearby family's homes Professional facilitator	QoL Subscales: Physical well-being Emotional well-being Self-esteem Family Friends School	Kinder Lebensqualitat (KINDL)	Significance level < 0.05 Overall QoL was non-significant Subscale: Family **Significant** $p = 0.018$ (Cohen's d 0.86, lge)
					Anxiety	RCMAS	Non-significant
Kobayashi et al. (2017) Japan *Children's Lives Include Moments of Bravery (CLIMB) – Japanese adaptation*	Exploratory quasi-experimental II, A/B3 sites	Examine intervention feasibility, and impact on child stress and parent QoL and psychosocial distress.	$n = 24$ parents $n = 38$ children (6-12 yrs) No controls	Int. University of Health & Welfare and the Tokyo Kyosai Hosp. Psychosocial oncology professionals	Psychosocial stress	Public Health Research Foundation-Type Stress Inventory (PSI)	Significance level ≤ 0.05 Non-significant
					PTSD symptoms	The Posttraumatic Stress Disorder-Reaction Index (PTSD-RI)	**Significant** $p = 0.010$ (effect size not reported).

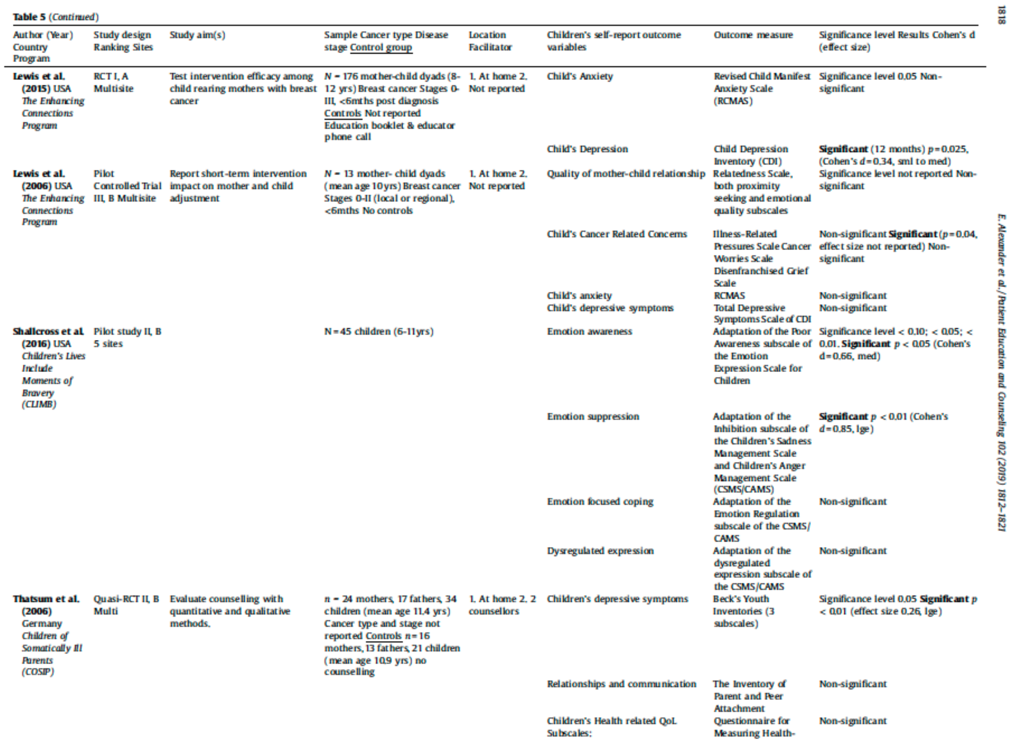

Table 5 *(Continued)*

Author (Year) Country Program	Study design Ranking Sites	Study aim(s)	Sample Cancer type Disease stage Control group	Location Facilitator	Children's self-report outcome variables	Outcome measure	Significance level Results Cohen's d (effect size)
Lewis et al. (2015) USA *The Enhancing Connections Program*	RCT I, A Multisite	Test intervention efficacy among child rearing mothers with breast cancer	$N = 176$ mother-child dyads (8-12 yrs) Breast cancer Stages 0-III, <6mths post diagnosis Controls Not reported Education booklet & educator phone call	1. At home 2. Not reported	Child's Anxiety	Revised Child Manifest Anxiety Scale (RCMAS)	Significance level 0.05 Non-significant
					Child's Depression	Child Depression Inventory (CDI)	**Significant** (12 months) $p = 0.025$, (Cohen's $d = 0.34$, sml to med)
Lewis et al. (2006) USA *The Enhancing Connections Program*	Pilot Controlled Trial III, B Multisite	Report short-term intervention impact on mother and child adjustment	$N = 13$ mother- child dyads (mean age 10 yrs) Breast cancer Stages 0-II (local or regional), <6mths No controls	1. At home 2. Not reported	Quality of mother-child relationship	Relatedness Scale, both proximity seeking and emotional quality subscales	Significance level not reported Non-significant
					Child's Cancer Related Concerns	Illness-Related Pressures Scale Cancer Worries Scale Disenfranchised Grief Scale	Non-significant **Significant** ($p = 0.04$, effect size not reported) Non-significant
					Child's anxiety	RCMAS	Non-significant
					Child's depressive symptoms	Total Depressive Symptoms Scale of CDI	Non-significant
Shallcross et al. (2016) USA *Children's Lives Include Moments of Bravery (CLIMB)*	Pilot study II, B 5 sites		N = 45 children (6-11yrs)		Emotion awareness	Adaptation of the Poor Awareness subscale of the Emotion Expression Scale for Children	Significance level < 0.10; < 0.05; < 0.01. **Significant** $p < 0.05$ (Cohen's $d = 0.66$, med)
					Emotion suppression	Adaptation of the Inhibition subscale of the Children's Sadness Management Scale and Children's Anger Management Scale (CSMS/CAMS)	**Significant** $p < 0.01$ (Cohen's $d = 0.85$, lge)
					Emotion focused coping	Adaptation of the Emotion Regulation subscale of the CSMS/CAMS	Non-significant
					Dysregulated expression	Adaptation of the dysregulated expression subscale of the CSMS/CAMS	Non-significant
Thatsum et al. (2006) Germany *Children of Somatically Ill Parents (COSIP)*	Quasi-RCT II, B Multi	Evaluate counselling with quantitative and qualitative methods.	$n = 24$ mothers, 17 fathers, 34 children (mean age 11.4 yrs) Cancer type and stage not reported Controls $n = 16$ mothers, 13 fathers, 21 children (mean age 10.9 yrs) no counselling	1. At home 2. 2 counsellors	Children's depressive symptoms	Beck's Youth Inventories (3 subscales)	Significance level 0.05 **Significant** $p < 0.01$ (effect size 0.26, lge)
					Relationships and communication	The Inventory of Parent and Peer Attachment	Non-significant
					Children's Health related QoL Subscales:	Questionnaire for Measuring Health-	Non-significant

Robb and Hanson-Abromeit [45] that identified interventions supporting children with cancer and their parents, reported twenty-two studies for review, including sixteen RCTs, compared to our two RCTs reported in this review.

A high level of clinical and methodological heterogeneity was observed, however, due to the small number of included primary studies and reporting quality, a formal review did not appear justified [46,47] and methods of narrative synthesis were employed to bring together results. Research designs were varied and sample differences such as disease type, stage, ethnicity, comorbidities, and other disease features were also evident. Intervention characteristics such as dose, duration, outcome levels (*e.g.*, length of follow-up), context, facilitator and timing also contributed to clinical variations. Caution regarding interpretation of findings is recommended. While outside the scope of this review, future reviews may consider a more in-depth exploration into heterogeneity by engaging with existing recommendations such as those set out by Gagnier and colleagues [47] to remedy issues associated with heterogeneity.

Consistent with findings from previous reviews [18,23], the methodological quality of studies in this review was not high. Studies were underpowered, lacked standardisation and randomisation, and sufficient levels of study control. Limited adherence to any form of standardised regulations or frameworks necessary to inform and guide study development and reporting, exacerbated this issue. Conformity to reporting guidelines and standards such as those outlined in the Consolidated Standards of Reporting Trials statement (CONSORT) [48], is recommended to ensure the accurate and transparent reporting of results [48,49]. No studies reported the inclusion of a theory necessary to inform the development and implementation of intervention strategies [50–52]. However, such a framework may not exist, thus warranting further investigation. The inadequacy of methodological quality in included studies, continues to challenge the capacity to confidently interpret research findings.

Outcomes related to depression appeared to be the most encouraging and amenable to intervention. Past reviews have also evidenced this [18]. Furthermore, the relationship between parent mental and physical related health problems and children's depression is well documented in the literature [53–56]. Psychoeducation, supportive counselling, building coping skills and communication enhancement were common components among interventions that successfully treated depression [24,26]. However, all components were broadly defined, and no studies investigated the relative contribution of components; therefore, it remains difficult to ascertain the mechanisms of change. Still, the literature does report the association of these components in therapeutic and maintenance roles among children with depression [56–58]. Therefore, these components warrant further investigation to delineate their potential capacity to alleviate depression in children of cancer patients. Also, the value of retaining components and their contribution to intervention success, should be thoroughly investigated to comply with principles of beneficence and nonmaleficence.

All four studies that evaluated anxiety failed to demonstrate significant improvement to this, despite evidence for higher levels of anxiety reported among cancer patients' children [59,60]. While Lewis et al. [25] did not detect change to levels of anxiety, possibly due to ceiling effects according to the authors, significant improvement was reported for children's cancer related concerns on one of three scales to assess this outcome. Notably, the authors report this scale was specific to children's worries attributed to their mother's breast cancer [25]. Other studies also reported significant findings on various outcome measures related to psychological distress [38,41]. How children are impacted and respond to their parent's cancer may fluctuate across time [12,15,17] and is influenced by various contending factors (*e.g.*, age, disease stage, family functioning) [10,61–63]. These results highlight the importance for identifying and assessing the correct outcomes using appropriate and sensitive tools.

A further explanation for the lack of significant results reported may be due to the appropriateness of assessment tools used by studies. For example, the ECP aimed to improve children's adjustment [25,26]. Yet, Lewis et al [26] only employed measures of children's anxiety and depression levels, as did Lewis et al. [25] additional to children's cancer related concerns. While, adjustment is a broad construct [64] the usefulness in measuring just two or three components of adjustment, is arguably futile. The contribution of further measures evaluating other components of adjustment or a validated tool specifically for children's adjustment, might be more successful in demonstrating intervention efficacy and producing relevant results.

Alternatively, Hauken et al. [39] investigated anxiety and QoL, and despite the methodological strength of their study and use of appropriate measures for these outcome variables, they too reported non-significant results, excluding the family functioning subscale on their QoL measure (KINDL). Notably, diminished family functioning is well supported within parental cancer literature [59,65]. Results suggest the diagnosis of a parent's cancer may impact more specific constructs of QoL, or that families receiving intervention are likely to maintain adequate functioning in these domains, while families not receiving intervention may deteriorate. Similar of adjustment, QoL is another broadly defined construct that is inherently subjective [27]. Current interventions may need to be more targeted in their approach to supporting specific processes underpinning the psychological vulnerabilities of children impacted by parental cancer. Hence, the literature may be aided by the provision of a theoretical model that conceptualises the impact of cancer on patients' children [3].

Children are highly embedded within systems, and intervention would be superfluous without appropriately engaging these [66]. However, interventions also need to ensure they are developmentally and age appropriate for children, and do not simply 'include' children. Most interventions in the current set were family- or mother and child- centred interventions. However, in the qualitative part of their study Thatsum et al. [24], reported some children did not feel adequately engaged within their family-centred program, with intervention counsellors spending more time or siding with parents. Despite using measures that are generally well validated among children, limited significant results were reported across studies, and this might be due to the limited number of child-centred interventions or tailorable programs with adaptive capacity to be child centric where necessary.

4.1.1. Study limitations

While this review was performed following a systematic process, there is possibility some papers were missed or have been published since our search. Furthermore, as we opted to exclude grey literature and non-English published papers, this may have omitted relevant information. However, steps were taken to reduce such omissions. While the decision not to engage a second rater for data extraction and synthesis may limit our ability to indicate the reliability of these processes, this was mitigated by continued and iterative discussions between the authors of this review, and through transparent reporting of the methods used.

The limited sensitivity of the quality rating tool employed in this review to critically appraise included studies is also acknowledged and might form a consideration for future reviews. While the tool by Keim-Malpass [37] enabled us to adequality organise our studies based on the quality of their contribution to this review, a more sensitive tool might expand on this by elucidating areas of study strengths and weaknesses. Though it appears no ‘gold standard’ tool exists, in their review Katrak et al. [67] suggest the properties and intent of the tool be used to guide researcher's decisions.

4.2. Conclusion

This systematic review explored the current interventions available for children living with parental cancer and focused on children's perspectives regarding intervention impact. We highlighted a growing body of evaluation studies that are yet to sufficiently meet the methodological rigour and quality necessary to be able to confidently interpret research findings. Current significant quantitative results are limited, inconsistent and conflicting across studies. There is some evidence to suggest current interventions can improve PTSD symptoms, emotional regulation and depression, however, are yet to be effective in other areas of concern, particularly anxiety. This warrants the need for more targeted, child-centred interventions and future validation studies that adhere to the appropriate intervention and methodological guidelines and adequately engage children in the evaluation process. It also highlights the lack of an existing model which conceptualises how children are affected by their parent's cancer diagnosis, subsequently providing a theoretical framework of how we might effectively and successfully intervene and support patients' children.

4.3. Future recommendations and practise implications

Through improved adherence to recommended guidelines and frameworks regarding intervention development, evaluation, and reporting, we suggest more methodologically robust studies be conducted to clarify and strengthen current research findings and promote this area of research. Future studies should also endeavour to further unpack and conceptualise our knowledge regarding how children are impacted by their parent's cancer, thus promoting our capacity for more targeted intervention among patients' children who are at risk. In doing so, the relative contribution of intervention components to intervention success should be defined, subsequently justifying their inclusion and adhering to principles of nonmaleficence. Finally, we encourage future research studies to engage with children and capitalise on the crucial pieces of information alternate sources such as parents and health professionals, are unlikely to yield. This will support future intervention research by promoting standardised levels of care among cancer patients' children, that is empirically supported, effective, and meets principles of non-maleficence.

Declarations of interest

None to declare.

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Chapter Summary

Chapter Two presented a systematic review of the current interventions available for patients' children and discussed the nature of these interventions and their effectiveness in supporting children. Six empirically evaluated interventions were identified and a detailed analysis of these interventions concluded interventions were not effective in mitigating children's psychosocial problems. Moreover, most interventions were not designed or evaluated using rigorous methodologies making it difficult to interpret research findings. For example, interventions were heterogeneous and comprised a broad range of characteristic features including psycho-education and supportive counselling. The quality of evaluation studies was low, with most reporting insufficient study power at follow up, absence of a control group for comparison, poor study control, and a lack of standardisation and randomisation. Furthermore, interventions and evaluation studies were not informed by a theoretical model conceptualising the experiences of patients' children when a parent is diagnosed with cancer, which may be due to the absence of such a model. Consequently, these methodological limitations contributed to the lack of significant and consistent findings reported across evaluation studies.

The purpose of this review was to inform the direction of the overarching study comprising this thesis. The findings of this review highlighted the need for more targeted, child-centred interventions and evaluation studies which adhere to intervention guidelines. Since this systematic review, there have been few interventions developed and reported in the empirical literature. These include a communication framework for health professionals and parents with cancer (Semple & McCaughan, 2019), a communication tool for adolescents with a parent with cancer (Hauken & Farbrot, 2021), an electronic games based intervention for parents with cancer and their children (Piil et al., 2021), and a psychosocial program (PEER) for adolescents impacted by a parent or siblings cancer diagnosis (Patterson et al., 2021). To support the development of more empirical interventions and evaluation studies for children living with parental cancer, a model explaining how children are affected by their parents' diagnosis was necessary. Such a model has not yet been proposed, therefore, this study developed a theoretical model of the underlying processes when a parent is diagnosed with cancer. A detailed rationale for this study, is provided.

Rationale for a grounded theory study

When a parent is diagnosed with cancer, their dependent children's overall adjustment and wellbeing is affected and they are vulnerable to developing various psychosocial, emotional, and behavioural problems (Morris et al., 2018; Walczak et al., 2018), which may impact some children long term (Bylund-Grenko et al., 2015; Lundberg et al., 2020; Stoppelbeing et al., 2006). Yet, other children demonstrate the potential for positive-traumatic growth and resilience building (Greening, 1992; Helseth & Ulfsaet, 2003, 2005; Osborn et al., 2017; Schmitt et al., 2008). While factors such as family functioning and parenting quality influence children's coping and adjustment to the diagnosis (Walczak et al., 2018), the mechanisms which underly this process remain unknown. Parents express their need for clinical help to support their children's needs, however, health professionals appear encumbered by barriers such as lack of time and developmental knowledge, which makes it difficult for them to provide this additional support (Dencker et al., 2019; Fearnley & Boland, 2017; Tafjord & Ytterhus, 2021). Moreover, there are limited child-centred interventions available to support children, and those that do exist are methodologically weak (Alexander et al., 2019; Niemela, 2010; Su & Ryan-Wenger, 2007; Walczak et al., 2018). Most interventions are void of theory and not evaluated using valid and reliable measures, rather they rely on informal qualitative feedback which makes it difficult to determine their effectiveness and suitability and to make comparisons against other interventions (Alexander et al. 2019; Niemela et al., 2010; Su & Ryan-Wegner, 2007). Consequently, findings across evaluation studies are ambiguous and inconclusive.

The findings from our systematic review confirmed our initial assumptions regarding the limited number of interventions available for patients' children, additional to the lack of methodological rigor observed across the development and evaluation of these interventions. This review also highlighted the absence of a theoretical model conceptualising how children are affected by their parents' diagnosis which contributed to the poor design quality observed in the intervention research and lack of significant findings reported across studies (Alexander et al. 2019). Interventions not informed by an appropriate theory increase the likeness of a Type III error, that is, the rejection of the effectiveness of the intervention when the intervention itself was insufficiently designed or delivered (Green, 2020). Furthermore, the absence of a theoretical model to inform intervention development contributed to the broad number of intervention components observed across interventions and the lack of evaluation determining their contribution to intervention success. Consequently, it cannot be determined that interventions supporting patients' children are adhering to principles of beneficence and nonmaleficence. Therefore, to improve the methodological rigor of future intervention research, and ensure that interventions are not eliciting more harm than good among children, the development of a model conceptualising the underlying mechanisms involved which influence how children are affected by their parents' cancer diagnosis, was warranted.

Hence, an exploratory study using methods of grounded theory was conducted, to provide an in-depth understanding of key informants' perspectives of parental cancer, which informed the development of a model conceptualising this experience.

Theoretical framework

Children are highly embedded within their external environment and the systems which surround them, including parents and family (Malin et al., 2016). Consequently, this context needs to be considered when exploring how children are impacted by their parents' cancer diagnosis, and the supports and resources that might be put in place to help them cope with and adjust to this. Bronfenbrenner's (1979) Ecological Systems Theory provides a strong theoretical framework for considering this context and therefore provides the underlying theoretical framework of this study. According to this theory, the child is situated in the centre of various interacting, self-regulating systems and subsystems: the micro-, meso-, exo-, and macro- systems (Bronfenbrenner, 1994). Some systems are proximal to the child (e.g., micro- and meso- systems) where their influence on the child's development is direct. However, other systems are positioned distally from the child (e.g., exo- and macro- systems) where their influence is indirect (Bronfenbrenner & Evans, 200). The dynamic nature of these systems, permit them to move in and out of proximity to the child, based on different circumstances. For instance, when a parent is diagnosed with cancer, systems such as friends and extended family may be moved outward from the child's miscrosystem to their exosystem, where their interactions are less frequent with the child. Alternatively, health professionals may be shifted into the child's microsystem where their interactions with the child directly influences their development. Therefore, according to this theory these interactions determine the child's psychosocial functioning and wellbeing (Bronfenbrenner, 1979; Issel et al., 1990).

Research aims and objectives

The overall aim of this study was to explore how children are affected by their parents' cancer diagnosis, from the perspectives of children, parents, and health professionals and develop an explanatory model conceptualising the underlying mechanisms involved which influence how children are affected by their parent's cancer diagnosis.

The specific objectives of this study were to:

- Explore oncology health professionals' perspectives regarding how children are affected by their parents' cancer diagnosis.

- Explore parents (including patients and partners of patients) perspectives regarding how their ability to support their children is affected when a parent is diagnosed with cancer.
- Explore children's perspectives of how they are affected by their parents' cancer diagnosis.
- Propose a model conceptualising the underlying mechanisms involved which influence how children are affected by their parents' cancer diagnosis.

Research questions

The research questions posed to achieve the research aim and objectives were:

- How do oncology health professionals perceive patients' children are affected by their parent's cancer diagnosis?
- How do parents (including patients and partners of patients) perceive their ability to support their children is affected when a parent is diagnosed with cancer.
- How do children perceive they are affected by their parent's cancer diagnosis?

Significance of the research

Most psycho-oncological research and practice to date has primarily focussed on improving our understanding of how to support patients and their spousal caregivers, however, there is increasing recognition of the challenges experienced by patients who are also parenting and the additional distress this elicits (Porter-Steele et al., 2017). As such, the impact a parent's cancer diagnosis has on their children is becoming a growing area of interest in research and clinical settings. With increasing survival rates among patients who likely have dependent children (AIHW, 2019) and trends to move treatment into out-patient settings, children are becoming more exposed to and burdened by the disease and treatment side-effects (Porter & Steele, 2017). However, there is a paucity of literature exploring how children are affected by their parents' diagnosis and little is known about the underlying mechanisms which influence children's coping and adjustment (Faulkner & Davey, 2002; Visser et al., 2004). Consequently, children are at risk for various internalising and externalising problems, which when left unaddressed may have significant long-term consequences (Morris et al., 2018; Walczak et al., 2018). Yet, parents are unsure how to support children and express their need for clinical and professional help (Dalton et al., 2019; Dencker et al., 2019). However, health professionals are challenged to facilitate this support (Dalton et al., 2019; Dencker et al., 2019; Tafjord & Ytterhus, 2021) and there are limited interventions currently available to assist children (Niemela, 2010; Su & Ryan-Wenger, 2007; Walczak et al., 2018). The interventions that do exist are methodologically poor and they are currently ineffective. Therefore, this study has contributed necessary and timely knowledge to parental cancer literature and clinical practice by providing an in-depth exploration of key informants' perspectives regarding how children are affected by their parents' cancer diagnosis. This knowledge has then informed the development of an explanatory model conceptualising children's experiences which may be used to improve the quality and rigor of future intervention research.

CHAPTER 3 Methodology

Chapter Overview

This chapter presents a detailed discussion of the methodological approach underlying the present study, which explored how children are affected by their parents' cancer diagnosis, from the perspectives of children, parents, and health professionals. The epistemological position of this study is justified, followed by an explanation of the theoretical framework and philosophical viewpoints which have informed the chosen research methodology. Following this, an in-depth description of constructivist grounded theory, the adopted methodology employed by this research study, is provided. An overview of the three studies comprising this study is given, additional to the procedures and steps, including data analysis, undertaken in each study. Details pertaining to the methods used are also reported in subsequent chapters. This chapter concludes with a reflexive piece detailing the personal motivations of the researcher for undertaking this research.

Paradigms

Khun defines research paradigms as a unitary set of beliefs that guide researchers and their research (Malterud, 2016). Two main research paradigms include: interpretivism and positivism. The present qualitative study was positioned within an interpretive paradigm due to the subjective nature of this research. The interpretive paradigm emphasises the individual's capacity to construct their own opinions of events (Crotty, 1998). It proposes notions about a particular social phenomenon or human experience are considered from different individual perspectives and it is these individual interpretations that people have of their social behaviours, which drives this approach to understanding meaning (Crotty, 1998; Weber, 1970). The underlying premise of interpretivism lies within an individual's meanings and motivations to act in a specific manner within different contexts (Ryan, 2018). From an interpretivist perspective, the researcher is focused on gaining insight into the individual’s or group’s social experiences, and typically uses qualitative methodologies that enable an in-depth exploration of these experiences (Crotty, 1998). Interpretivism emphasises the meanings that individuals prescribe to events, thus adopting a micro-level approach to sociology, rather than looking at the broader narrative of society (Wilson, 1970). Moreover, this approach recognises the free will and agency of individuals, and their capacity to act differently within situations despite the confines of social structures in which they are embedded (Crotty, 1998; Wilson, 1970).

In contrast to interpretivism, positivism is a form of macro sociology that is concerned with the impact of social forces and how these shape individual behaviours (Comte & Thompson, 1976; Crotty, 1998). Positivism explores the larger societal picture rather than the interactions of individuals. Hence, positivists emphasise the social institutions (e.g., family, education) that shape society and an individual’s behaviours, therefore adopting a more structural view of society (Comte & Thompson, 1976). Subsequently, positivism typically uses quantitative research methods as it considers society can be studied in the same way as the natural sciences, thus preferring objective and generalisable quantitative data over qualitative data which requires value judgement for analysis (Crotty, 1998). Positivism therefore allows the researcher to propose a cause-and-effect relationship between social institutions and individuals in society (Crotty, 1998; Park et al., 2020). Contemporary understandings of positivism are predominantly aligned with the empirical sciences and therefore diverge distinctly from other methods of research that value opinions, beliefs, feelings, and assumptions (Park et al., 2020). Research situated in this paradigm is therefore primarily focussed on prediction and null hypothesis testing, which consequently contracts the nature of exploration and finding meaning available within other paradigms of research (Park et al., 2020).

Explanation of the pertinent philosophical, theoretical, and methodological underpinnings that were chosen to guide this research study will be governed by Crotty’s (1998) model (see Figure 1). This model conceptualises and organises qualitative research using four components: the epistemological position, theoretical perspective, methodology, and methods. As such, this chapter will provide a defensible perspective regarding the chosen research process used in this study, and the methodology and philosophical assumptions that underpin this process.

Figure 1. The four components of Crotty's (1998) model which inform research decisions.

Based on Crotty's (1998) model, the following sections in this chapter discuss firstly the epistemological position of this research study by presenting an outline of three major epistemologies, objectivism, subjectivism, and constructionism. This discussion enables an explanation and justification for the decision to adopt the viewpoints inherent to a constructionist epistemology. Following this positioning of the research, a further discussion of the origins of constructionism are presented in an overview of Jean Piaget's (1971) constructivism, proceeded by a detailed account of Seymour Papert's (1980) constructionism. Social constructionism is then presented as a derivative of constructionism, as it addresses proposed limitations of constructionism and incorporates explanations for the key role social aspects have in knowledge construction, (Burr & Dick, 2017), which are fundamental of the present research study. The next section details the theoretical framework underlying this study, which comprises the second component in Crotty's (1998) model. In this study, an integrated theoretical approach using Blumer's (1969) Symbolic interactionism and Bronfenbrenner's (1979) Ecological systems theory is used, and justification for this is provided. This section is proceeded by an in-depth discussion of the methodology employed, Kathy Charmaz' (2006, 2014) constructivist grounded theory, which is the third component in Crotty's model. An overview of the origins for this methodology, Glaser and Strauss' (1967) grounded theory, is also provided. Lastly, this chapter concludes with a description of the final component in Crotty's (1998) model, the specific methods used to action this research study.

Epistemology

Epistemology concerns the nature, scope and origin of knowledge; that is, it presents a way of understanding and explaining "*how we know what we know"* (Crotty, 1998, p. 8; DePoy & Gitlin, 1998). It provides the philosophical grounding for the kinds of knowledge that are possible and provides the means for ensuring the adequacy and legitimacy of this knowledge (Crotty, 1998). Therefore, the epistemological position adopted by the researcher, is inherent to the theoretical perspective and methodologies used in the research study. Research designs adopting a purely positivist approach, often underpinning quantitative studies, generally apply epistemologies that are deductive (top-down) in nature (Park et al., 2020). Deductive research approaches attempt to explain a phenomenon through beginning with a premise or belief that are prefaced by a testable hypothesis(es) (Hyde, 2000). Alternatively, the epistemologies of qualitative studies assume knowledge is inferred though inductive (bottom-up) and abductive (the most likely) processes (DePoy & Gitlin, 1998). In these situations, research starts with a situation or observation and then attempts to identify patterns which explain a broader understanding of the phenomenon (DePoy & Gitlin, 1998).

A range of epistemologies exist; however, Crotty (1998) focuses on three major epistemologies: objectivism, subjectivism, and constructionism. *Objectivism* typically informs a positivist research paradigm and insists that meaning and therefore a meaningful reality is not tied to human consciousness (Crotty, 1998; Diesing, 1996). That is, an object holds intrinsic meaning and is simply awaiting discovery by human beings. This epistemology adopts a systematic philosophy based on an objective reality and an objective truth that exists outside of any form of human consciousness, which requires a detailed, organised, and methodical study of the nature of existence, reality, and knowledge (Crotty, 1998). For example, everyone is born and everyone dies, their existence is an objective fact. S*ubjectivism* is the philosophical tenor that our own mental activity is the only unquestionable element in our experience of the world (Crotty, 1998; Diesing, 1996). There is no external or objective truth waiting to be inherently discovered within an object (objectivism), nor is meaning the constructed product of a dynamic interplay between the object and human beings (constructionism) (Crotty, 1998). Rather, meaning is subjective and derived from elsewhere, including our collective unconscious, and then imposed upon an object (Diesing, 1996). For example, an individual's subjective thought might perceive cancer as a terrifying and deadly disease.

The third major epistemology Crotty (1998) refers to is *constructionism,* which adopts the viewpoint that people construct meaning and understanding of the world they are trying to interpret based on their conscious interactions and participation in it. Therefore, constructionism is the epistemological position underpinning this study. Constructionism is neither objective nor subjective, instead it reflects notions that objectivity and subjectivity should be held together indissolubly (Burr, 2017; Crotty, 1998) In the present study, this epistemology considers the constructed meaning of parents, children, and HPs experiences during a parental diagnosis of cancer, through how they interpret their social interactions in the world. Constructionism is particularly suited to this research study as it highlights the dynamic nature of the individual and emphasises the social aspect of human beings, acknowledging language as integral to this, which is contrary to the individualistic nature of earlier epistemologies (Burr, 2017; Fosnot, 1996). This also supports the sociable and impressionable nature of children who are highly embedded within their social systems, and the dynamic nature of their development (Zandt, 2017).

Constructivism

Jean Piaget's epistemological theory of 'constructivism' explains how individuals construct meaning through interactions between their cognitive processes and their experiences (Piaget, 1971). Founded in developmental psychology, this theory provides insight into children's interests and achievement capacity, by focusing on explaining their evolving thoughts and the nature of their behaviour at different stages of development (Ackerman, 2001). According to Piaget, children (and adults) mentally construct knowledge and experience through internal cognitive processes based on complex laws of self-organisation (Piaget, 1967 Ackerman, 2001). For example, through the processes of assimilation and accommodation the individual integrates knowledge into pre-existing schemas (assimilation) or changes schemas to fit the individual's environment (accommodation) (Piaget & Inhelder, 1969). However, this theory does not consider the role of the context, uses, and media, and individual preferences and differences (Ackerman, 2001). This can be overcome through integrating Papert's definition of constructionism, which presents a more comprehensive view of how individuals come to make sense of their experiences through increasingly enhancing their interactions with the world (Ackerman, 2001).

Constructionism

Seymour Papert built on the theory of constructivism to define '*constructionism'*, by retaining Piaget's view that learning occurs through reconstruction (rather than a transmission) of knowledge, while also incorporating the notion that learning is most effective when part of the activity is meaningful to the learner (Ackerman, 2001; Papert, 1980). According to constructionism, the world is void of meaning until experienced by human consciousness and it is only upon engaging in their world that individuals can construct meaning (Crotty, 1998; Papert & Harel, 1991). Moreover, without this conscious capacity of human beings and their ability to interpret the world, the world and the objects that exist within it, have no meaning (Crotty, 1998). Hence, meaning does not simply exist within the object itself, nor is it created from our subconscious; rather it is awaiting the individual to come upon the object and *discover* its meaning. That is, we are given the tools and materials (the world and objects in the world) necessary to work with, and construct meaning from.

Like Piaget, Papert also adopts a constructivist approach that is founded in developmental psychology and emphasises the cognitive component of knowledge acquisition (Ackerman, 2001). However, a fundamental difference between constructivism and constructionism lies within their interpretation of intelligence and how it should be studied (Ackerman, 2001). While Piaget's interests were mainly in the construction of an internal stability, Papert focused on the dynamics of change (Ackerman, 2001; Papert, 1980). Piaget considered the learning process to be increasingly disconnected from the situation as children's cognitive sophistication increases and they are capable of imposing order over their changing environment (Ackerman, 2001; Piaget & Inhelder, 1969). Alternatively, Papert viewed this process as *in-situ*, whereby children actively and curiously connect with the situation and learn from their experiences rather than having this knowledge imparted upon them (Ackerman, 2001; Papert & Harel, 1991).

Central to constructionism, is the concept of *intentionality,* from the Latin *tendre*, meaning 'to tend' (Crotty, 1998). It refers to directedness, referentiality, and relatedness, and lends itself to notions of 'directing oneself' or 'moving toward' (Crotty, 1998). Hence, intentionality is not about choosing, planning, or deliberating, rather it is about reaching out into. Thus, underlying intentionality is the premise that "when the mind becomes conscious of something, it reaches out to, and into, that object" (Crotty, 2003, p 44). For example, for an individual who has witnessed the death of a family member due to cancer, their constructed meaning of cancer might be that it is a devastating, life limiting illness. This same individual might then encounter another individual whose cancer is in remission, and their constructed meaning of cancer might now be that it is a devastating, life limiting illness that in some cases is treatable. This focus on the interaction between the individual and the object is crucial to constructionism as it is from this interaction that the individual's knowledge of the world and its objects, is constructed (Ackerman, 2001; Papert & Harel, 1991).

Since its original conceptualisation, constructionism has attracted criticism (Crotty, 1998; Martin & Sugarman, 1996). For instance, existential phenomenologists would later broaden the lens of constructionism by shifting the focus off the cerebral to considering the individual in their entirety (Crotty, 1998; Gergen, 2010). They recognised that not only is the conscious mind intentional, but human beings themselves are intentionally related to their world (Gergen, 2010). An individual's experiences are not subjectively held separate to the objective world, rather both are interdependent of one another. More recently, many within this growing field have considered constructionism to be limited by its reliance on the individual's self-governing process of cognitive construction, thus disregarding the social aspects of humans and the role this yields in knowledge construction (Martin & Sugarman, 1996). That is, constructionism emphasises a highly individualistic approach and does not consider other factors, such as the role of social interaction, culture, and context (Young & Collin, 2004). This limitation of constructionism is somewhat addressed by those who adopt a social constructionist approach, which considers the social nature of meaning construction (Bruner, 1990; Vytgotsky, 1978).

Social Constructionism

Social constructionism considers the social origin of meaning and subsequently assumes a social approach, which is contrary to the individual stance adopted by constructionism (Crotty, 1998; Burr & Dick, 2017). While constructionism emphasises the individual's biological and cognitive processes in the construction of knowledge, social constructionism places knowledge in the domain of social interchange (Burr, 2015). Social constructionism asserts that meaning is constructed through historically and culturally specific interactions between relevant social groups (Gasper, 1999). Therefore, meaning and social action are inextricably linked. According to Fish (1990), the 'means' by which meaning is constructed are social and conventional institutions that precede us and in which the individual is already embedded. For example, women are caregivers and men are providers. Subsequently, these systems of intelligibility that are available to all, provide interpretive strategies from which meaning can be constructed (Fish, 1990).

According to the American anthropologist, Clifford Geertz the means for constructing meaning is culture, which he articulated as a system of significant symbols (Geertz, 1973). Consequently, culture is crucial to human functioning as it is necessary in directing individuals' behaviour and experiences (Crotty, 1998). Rather than traditional approaches where culture is considered the product (e.g., customs, traditions, and habits) of thought and experience, Geertz (1973) considered culture as the source that informs human thought and behaviour. From this viewpoint, culture is a set of predetermined mechanisms or instructions that govern behaviour, thus implying that human thought emerges as both social and public. As such, the symbols inherent to culture already exist in society and are 'given' to the individual upon birth and will exist beyond their death. Therefore, from a social constructionist perspective, individuals are born into a world that already bears meaning (Crotty, 2003; Gemignani & Pena, 2007). That is, we inherit a system of significant symbols (culture) that provides us with the lenses through which we perceive and make meaning of the world.

However, as Harre et al. (1986) highlights, the reductionist nature of this epistemology fails to consider the complex construction of human emotion, instead focusing on the overlay of culture and language on biology in this process, and minimising other aspects such as physiological ones. For constructionists, local language and the local moral order are the two social matters which greatly affect the individual's experience of emotion, thus stressing the cultural relativity of emotions (Harre et al. 1986). As such, this viewpoint limits the psychological study of emotions with little offered by constructionists to rectify this issue of cultural relativism (Harre et al. 1986; Wouters, 1990). Furthermore, the perspective that emotions are shaped by the individual's social and cultural context risks negating the cross-cultural similarities observed in people's emotional experiences (Boiger & Mesquita, 2012; Mesquita, 2001; Mesquita & Frijda, 1992). Rather, a dynamic and interactive approach to the social construction of emotions is suggested, to mitigate the likeliness of oversimplifying the nature of emotions, including how they are experienced, perceived, and communicated (Boiger & Mesquita, 2012). This approach might also benefit from other disciplines including sociology and anthropology (Boiger & Mesquita, 2012). For instance, sociological theories of symbolic interactionism emphasise the role of one's self-perception in the development of positive and negative emotional responses to the individual's cognitive appraisal of social situations (Boiger & Mesquita, 2012; Turner 2009).

Theoretical Framework

The theoretical framework of a research study is the philosophical viewpoint that explains and provides the context for the chosen methodology used in a research study (Crotty, 1998). This is informed by the epistemology, as indicated by Crotty's (1998) model (see Figure 1). There are a number of assumptions that inevitably underlie the chosen methodology used by a researcher, and it is important these are presented as they are understood by the researcher. Symbolic interactionism is the theoretical framework that informed the methodologies of this study (Blumer, 1969). Symbolic interactionism is a micro-level sociological theory that focuses on how people interpret the behaviour of others in social interactions, and thus how this informs their own behaviours (Blumer, 1969; Crotty, 1998). Moreover, this theoretical framework proposes that through language and communication, symbols enable human beings to construct meaning. Therefore, this framework encourages qualitative methodologies that allow the researcher to focus on the social interactions and behavioural interpretations observed among key informants, and to understand the language and communication they use to construct meaning of their realities (Crotty, 1998). However, while symbolic interactionism explains how an individual’s actions are influenced by how they interpret their social interactions, it does not address environmental components (Ali, 2021). Therefore, ecological systems theory (Bronfennbrenner, 1979) was also used in this study to provide a contextual lens through which symbolic interactionism was viewed.

Symbolic interactionism

Symbolic interactionism originated in the early 20th century from the teachings of George Herbert Mead, a pragmatic philosopher and social psychologist who contended that human development and the meanings people assign to objects is a social process (Crotty, 1998; Blumer, 1969). The underlying premise of symbolic interactionism states that people are subject to change based on their interactions with the world, including objects, events, ideas, and other people, and the meanings they attribute to things in order to decide how to act (Blumer, 1969). Inspired by his work, students of Mead later compiled his teachings into a book titled, *Mind, self, and society* (Mead, 1934), and one student, Herbert Blumer went on to further Mead’s work by presenting his own version of this sociological theory which he coined symbolic interactionism (Blumer, 1969).

Symbolic interactionism refers to the unique nature of social interactions observed between human beings (Blumer, 1969). Rather than simply reacting to one another’s actions, people instead define and interpret their actions. An individual’s response to these actions is then based on the meaning they attribute to them. Inherent to symbolic interactionism is the use of *symbols* in communication (Carter & Fuller, 2015; Denzin, 2004). Symbols are culturally derived social objects that have a shared meaning and are created and maintained through social interaction and are therefore considered unique to human beings (Carter & Fuller, 2015). Symbols are the basis for all human communication, and it is through language and communication that symbols provide the means for which meaning and reality are constructed. Therefore, studies framed by symbolic interaction typically use qualitative research methods, given that their predominant focus is to understand the symbolic words that construct the reality in which the participant exists (Crotty, 1998).

According to Blumer (1969), Mead elevates this understanding of interpretation from the descriptive to the analytical by proposing what this act of ‘interpretation’ means for the nature of the human beings and human association. Blumer (1969) presents this as three major assumptions that underly symbolic interactionism. The first being that the individual acts based on the meaning they have given an object or symbol. The second being that individuals assign meaning based on their social interactions; hence, the same object could have a different meaning for different people. The third assumption being that the meaning an individual assigns to something is not permanent, rather it can change due to everyday life. Therefore, the focus of this theory lies in meaning, which is defined by action and consequence, thus reflecting the pragmatic philosophical roots in which symbolic interactionism is embedded (Blumer, 1969; Carter & Fuller, 2015).

Contemporary perspectives of symbolic interactionism suggest the focus of this theory and the questions it proposes are different to those that are characteristic of large-scale sociological theories (Musolf, 1992). Therefore, symbolic interactionism is often considered a micro-level sociological theory because it focuses on unpacking the small interactions between individuals (Carter & Fuller, 2015). When examining society from a small-scale perspective, symbolic interactionism attributes the same level of importance to the individual that it does to society as a whole. Symbolic interactionism explains how aspects of society are capable of change as they are created and re-created by social interactions, thus providing a different perspective to sociology, which articulates the necessity of understanding society in its entirety.

However, while symbolic interactionism provides an understanding of the specific nature of the interactions that occur between systems (i.e., how individuals interpret their social interactions, which then inform their own actions), it does not provide insights regarding the systems in which these interactions occur, or the underlying systemic complexities that exist within and between systems (Ali et al. 2021). To address this, Thornburg (2017) suggests adopting a synergised approach using symbolic interactionism and systems theory, to provide a more comprehensive insight into the social phenomenon under investigation. In a study investigating school bullying, Thornburg (2017) used a modified ecological model originally proposed by Migliaccio and Raskauskas (2015), which integrates the social-ecological theory with symbolic interactionism. In doing so, this enabled the author to consider the power imbalances that occur with bullying, as greater than the relationship between the bully and the victim (Migliaccio & Raskauskas, 2015). Rather this relationship is situated within complex layers of social forces that enable bullying to occur (Migliaccio & Raskauskas, 2015). Therefore, by adopting this approach, the present study considered how children are affected by their parent's cancer diagnosis as more than the relationship between parent and child; extending this thought to other social forces which impact this social phenomenon.

Ecological systems theory

The chosen systems theory used in this study was Urie Bronfenbrenner's (1979) Ecological Systems Theory, which provided a lens for considering the complex and dynamic systems and subsystems cancer patient's children are embedded within, and the social forces which influence how they are affected by their parent's cancer diagnosis. This comprehensive theory examines the broader contextual factors which influence a child's development and experiences beyond their personal characteristics (Bronfenbrenner, 1994; Bronfenbrenner & Evans 2000). In this conceptual framework the child is situated at the centre of multiple concentric, self-regulating, and interacting systems: the micro-, meso-, exo-, and macrosystems (see Figure 2 for example) (Bronfenbrenner, 1992).

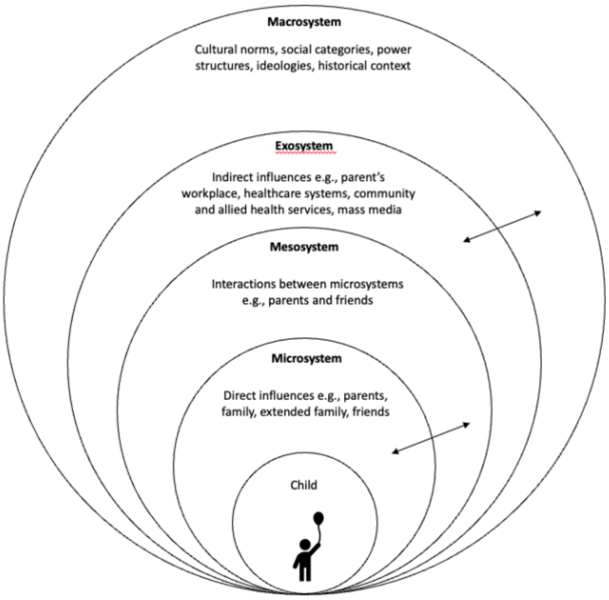

Figure 2. Adaptation of Bronfenbrenner's (1989) Ecological Systems Theory model depicting an example the systems and subsystems that affect the developing child.

The level of influence these systems have on the developing child diminishes with proximity, with those that are situated closest to the child having the most influence, and those positioned further away having a lesser influence (Bronfenbrenner, 1992). The *microsystem* is the closest system to the child and represents the relationships and interactions that are in closest proximity to the child and directly influences their development (e.g., parents, friends) (Bronfenbrenner & Evans, 2000). The *mesosystem* represents the interrelationships that occur between multiple subsystems within the microsystem (e.g., between parents and friends). The *exosystem* refers to subsystems that have an indirect influence on the child's development (e.g., a parent's workplace might elicit a toxic work culture which impacts their mental health and their relationship with their child). Lastly, the *macrosystem* consists of the overarching culture that houses the developing child and the micro- and mesosystems embedded within that culture, lending this system to evolve across time (e.g., cultural norms, ideologies).

However, the dynamic nature of these systems permits the changing proximity of subsystems both within and between systems (Bronfenbrenner & Evans, 2000) thus lending these systems to evolve differently when a child's parent has been diagnosed with cancer (see Figure 3 for example). For example, most children are unlikely to have had much interaction with oncology health professionals and hospitals (Alexander et al., 2020; Dencker et al. 2019). However, following a parent's cancer diagnosis, these are pertinent relationships and interactions that move into patients' children's microsystems, through visiting their parent in hospital, attending appointments, hearing parents' conversations, and witnessing a parent's response to treatment. Therefore, it is paramount health professionals are aware of this influence and how these interactions will have a direct impact on children's development (Dencker et al., 2019). Furthermore, children's mesosystems also transform with the interrelationships between microsystems, such that parents, health professionals, and hospitals become central in the developing child's environment.

While the focus of the present study was primarily directed at children's micro- and mesosystems, importantly, the influence of the child's exo- and macrosystems was also considered. At the exosystem level, subsystems such as healthcare systems and parents' workplaces have an indirect influence on patients' children. For example, while patients' children are unlikely to come into contact with possible inequities in healthcare systems, these will indirectly influence children through the disadvantage experienced by their parents and the impact this has on their health outcomes. Macrosystems such as cultural norms and social categories will also indirectly influence how patients' children are affected by their cancer diagnosis. For example, people with a lower socioeconomic status may have less access to adequate healthcare services, support networks to help look after children, and lower levels of health and psychological literacy, which challenges their capacity to seek necessary medical treatment and support for themselves and their children (Blendon et al., 2002).

This framework also proposes these subsystems will move in and out of micro-, meso- and exosystems across time, as patients' treatment progresses and children inevitably mature, and the overarching culture will also evolve at the macrosystems level (Bronfenbrenner, 2005; Bronfenbrenner & Evans, 2000; Spencer, 2007). For example, at the point of diagnosis and the onset of treatment, children generally experience much disruption to systems and subsystems, as hospitals and health professionals move into their micro- and mesosystems and existing subsystems, such as friends and school, are pushed out into outer layers. As the parent's treatment program comes to an end and they enter remission, hospitals and health professionals will move distally and other subsystems will enter the child's micro- and mesosystems, including the return of friends and school. It is important to recognise how systems are likely to change for children at various stages during their parent's cancer diagnosis, as the presence (or lack thereof) of subsystems directly influences how children are affected. For example, losing their connections with friends and school during diagnosis can be upsetting for many children, rendering them isolated and alone and impacting on their capacity to cope (Alexander et al., in review; Morris et al., 2018), which is further elaborated on in chapter 6.

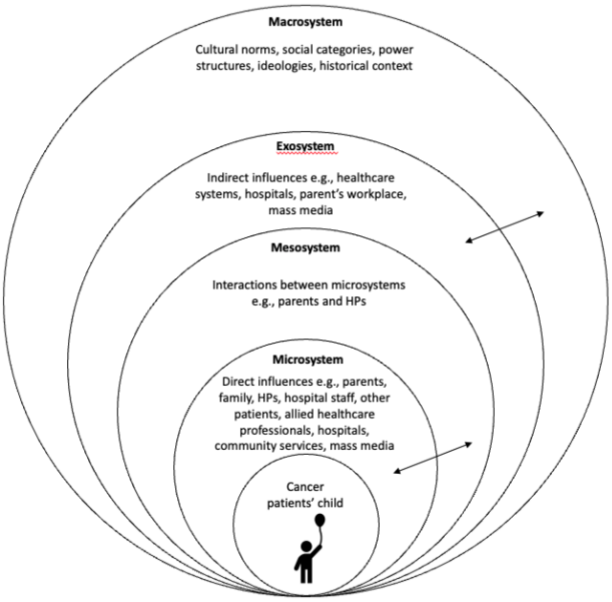

Figure 3. Adaptation of Bronfenbrenner's (1989) Ecological Systems Theory model depicting an example of the systems and subsystems that influence how children are affected when a parent is diagnosed with cancer.

An integrated theoretical approach combining symbolic interactionism and ecological systems theory (Thornburg, 2017) was used to consider participants' constructuction of meaning through their interpretations of their social interactions (symbolic interactionism) (Blumer, 1969). This approach also provided a lens to examine the complex nature of the systems in which these interactions occur (ecological systems theory) (Brofenbrenner, 1979), thus presenting a comprehensive philosophical viewpoint for the chosen methodology. The theoretical framework of this study lends itself to a methodology that enables the in-depth exploration of participants' constructed and interpreted meanings of how children are affected by their parent's cancer diagnosis, while remaining sensitive to the interrelationships between the individual and contextual factors. As such, the integration of symbolic interactionism and ecological systems theory acknowledges both agency and structure and encourages a methodology that is flexible enough to embrace this (Thornburg, 2017).

Anslem Strauss, a sociologist who came from a symbolic interactionist perspective developed the qualitative methodology- grounded theory, alongside Barney Glaser (Glaser & Strauss, 1967) just prior to the 'interpretive turn' in the 1970's (Clarke, 2021). Central to the interpretive turn was the proposition that greater attention needs to be directed toward the way in which social interactions are embedded within social contexts (Wilson, 1970). As such, Strauss then sought to incorporate more structural and contextual sensitivity in doing grounded theory (Clarke, 2021). Kathy Charmaz, a student of Strauss who was influenced by his symbolic interactionist and pragmatic perspective, later developed her own version of grounded theory- constructivist grounded theory, which emphasises the individual agency and the context in which the individual is embedded within, in the construction of meaning (Charmaz, 2014; Guba & Lincoln, 1994). Therefore, due to its capacity to provide a deep analysis of participant's constructed meanings, and flexibility to consider the broader context in which participants are situated in (Charmaz, 2014), this methodology was deemed appropriate for the present study.

Methodology

The third component in Crotty's (1998) conceptual model (see Figure 1) is the methodology which is informed by the theoretical framework and denotes the strategy or plan of action employed by the research study. Ultimately it serves to inform the researcher's choice in methods as linked to the desired research outcomes (Crotty, 1998). By appropriately describing the methodology, this provides the reader with the rationale adopted by the researcher for the methods used in the research study (Crotty, 1998). The methodology used in this study was Kathy Charmaz' version of Glaser and Strauss' classic grounded theory - *constructivist grounded theory* (Charmaz, 2006; 2014). This methodology is consistent with the theoretical framework underlying the present study as it enables the in-depth analysis of key informant's interpreted meanings that are constructed through their social interactions (Blumer, 1969). Furthermore, its philosophical underpinning acknowledges children as active agents in the development of their own culture

(Charmaz, 2006), and its flexible methodological application allows the researcher to more broadly consider the complex interplay between contextual and individual factors (Thornburg, 2017).

Grounded theory

Historical context of grounded theory.

Before the components of grounded theory can be discussed, it is important to acknowledge the historical context from which this methodology originated to provide an understanding of its tenets, affordances, and variations (Dunne, 2011). In the mid- 1960s grounded theory was developed by Barney Glaser and Anslem Strauss during a time when quantitative research and deductive ideologies dominated research methods, while qualitative research could not adhere to the stringent criteria utilised by quantitative research (Charmaz, 2006, 2014; Dunne, 2011). During this time, many questioned the methodological legitimacy of qualitative research, which, until this point, had been considered anecdotal, biased, and impressionistic (Charmaz, 2006, 2014; Dunne, 2011). To address these criticisms, Glaser and Strauss bought together their ideological backgrounds and research methods training, to produce a qualitative methodology that combined both quantitative and qualitative traditions. This methodology was first articulated in their book titled *The Discovery of Grounded Theory* (Glaser & Strauss, 1967). Glaser who came from a positivist background and had been trained in empirically driven quantitative research methods, contributed the objective and rigorous properties, namely the constant comparison method, that are inherent to grounded theory (Stern, 2009). Strauss who came from a symbolic interactionist perspective (originating from pragmatism) and was trained in theory generation, contributed the approach of using individual stories to understand social processes (Stern, 2009). The result of this being the formation of a methodological process that is both deductive and inductive in its approach to theory generation (McGhee et al., 2007), and which has since gone on to become one of the most commonly used analytic techniques in qualitative research (Bryant & Charmaz, 2007; Case & Light, 2011; Greckhamer & Koro-Ljungberg, 2005).

The central tenet of grounded theory is the belief that social phenomena can be understood through a systematic research process guided by the participant's experiences; ultimately resulting in a theory that explains patterns within those experiences (Glaser & Strauss, 1967; Hood, 2007). Hence, despite common assumptions that grounded theory is a theory within itself, it is rather a way of discovering theories that are grounded in the data. The theory that is produced is one that is inductively derived through researching and studying the social phenomena at hand (Strauss & Corbin, 1990). The researcher's objective is to 'generate' these explanations of the data, from the data itself, rather than having a predetermined set of hypotheses or theoretical assumptions prior to commencing the study. Moreover, in its most extreme form, grounded theory assumes that the researcher will begin the research process *tabula rasa* (a clean slate), that is with no knowledge or preconceptions of the phenomena under investigation (Mills et al., 2006). There are a number of core elements which are essential to grounded theory (Charmaz, 2014; Bertero, 2012; Hallberg, 2006) which can be summarised as follows:

1. *The researcher's line of inquiry is shaped by the aim to discover social and psychological processes.*

Founded in sociology, Glaser and Strauss (1967) originally proposed grounded theory for application in social and psychological research. However, due to the descriptive nature of grounded theory, and its capacity to generate theory, it has since gone on to be used in a variety of fields, including medical sociology (e.g., Charmaz, 1990), education (e.g., Hachtmann, 2012; McKenna & Millen, 2013), nursing (e.g., Häggström et al., 2012; Williams, 1998), and engineering (e.g., McCall, McNair & Simmons, 2021).

2. *Data collection and analysis phases occur concurrently.*

Theoretical sampling techniques enable the researcher to sample participants while concurrently analysing the data and lends itself to determining data saturation.

3. *The analytic process employed prompts theory discovery and development, rather than verifications of pre-existing theories.*

Grounded theory methodologies assume an inductive or abductive approach whereby theory is grounded within the data itself (Charmaz, 2006; 2014). Traditional grounded theory methodologies demand the researcher approaches the research process *tabula rasa*, void of predetermined assumptions or hypotheses, as would typically be observed in a purely positivist paradigm (Mills et al., 2006).

4. *The systematic application of grounded theory analytic methods will progressively lead to more abstract analytic levels* (Charmaz, 1983, p. 125)

Methods of constant comparison enable the generation of codes that move from the descriptive levels of coding through to the more analytical or theoretical levels. To achieve this, the researcher should ask analytic questions of early codes. To be analytic means to break up the data and see what comprises it i.e., the properties and conditions under which it exists (Charmaz, 2014).

Different versions of grounded theory.

The version of grounded theory discussed up until this point, is considered *classic grounded theory,* however, since its original conceptualisation, different versions of this have arisen based on adaptations of various scholars to suit their own ontologies, epistemologies, and research contexts (McCall & Edwards, 2021). Common versions of these are *pragmatic grounded theory* (Strauss & Corbin, 1990, 1994) and *constructivist grounded theory* (Charmaz, 2006, 2014), both of which are housed in the second generation of grounded theory (Charmaz, 2014) and are paradigmatically different to Glaser and Strauss' (1967) classic version. The paradigmatic differences between classic, pragmatic, and constructivist grounded theory are summarised in Table 1. Tensions among these versions and confusion generated by their differences, has since arisen with ongoing debate regarding grounded theory's implementation and outcomes (Bryant & Charmaz, 2007; McCall & Edwards, 2021) and furthermore, what constitutes high-quality grounded theory research compared to poorly designed qualitative research studies claiming to be grounded theory (Baker et al., 1992; Bello, 2015; Suddaby, 2006).

Table 1.

Paradigmatic Assumptions and Characteristics of Grounded Theory (GT) Methodology (adapted from Groen et al., 2017).

	Classic GT (Glaser & Strauss, 1967)	Pragmatic GT (Strauss & Corbin, 1990, 1998)	Constructivist GT (Charmaz, 2006, 2014)
Ontology	Critical realist	Interpretivist	Constructivist
Epistemology	Objective	Pragmatic	Subjective

Researcher role	Observer	Interpreter	Integrated co-constructor
Purpose	Abstract theory and meaning	Abstract theory or to gain an in-depth understanding	Abstract theory and in-depth meaning
Implementation	Promotes adherences to rigorous, fundamental processes	Provides a set of tools that may be used, rejected, ignored	Highlights flexibility within the process; resists mechanical application
Outcome	Generalised theory that transcends time and context	Subjective theory dependent on time and context or descriptive non-theory	Subjective, descriptive theory dependent on time and context

Constructivist grounded theory

Historical context and philosophical underpinnings of constructivist grounded theory.

Kathy Charmaz' *constructivist grounded theory* (2006, 2014) forms the methodological approach used in the present study as it adopts more adaptive methods and also considers the co-construction of meaning and experience between participant and others, including the researcher. This version of Glaser and Strauss' (1967) classic grounded theory is informed by Charmaz' relativist ontology and subjective epistemology that proposes reality is individually constructed and therefore there are many forms of reality (McCall & Edwards, 2021; Guba & Lincoln, 1994). Earlier versions of grounded theory adopt a more modernist and objective worldview that propose meaning is discoverable. However, Charmaz' post-modernist worldview focuses on the constructed nature of meaning that is dependent upon the individual and their environment, which is emphasised by the methodological contingency placed on the co-construction of knowledge between the participant and the researcher (Charmaz, 2014; Guba & Lincoln, 1994). A student of Anslem Strauss, Charmaz was influenced by his symbolic interactionist perspective and iterative research approaches (McCall & Edwards, 2021). Subsequently, these components of classic grounded theory are retained in constructivist grounded theory, however, Charmaz' version diverges from this through her emphasis on the individual agency one has in making meaning that is associated with constructivism (von Glasersfeld, 1995). According to Charmaz, knowledge about reality depends on the context in which the individual is embedded within and is co-constructed through their interpretation and meaning making of their interactions with others and conversely how others act in different situations (Charmaz, 2014; Guba & Lincoln, 1994). Thus, the theory generated by grounded theory research is a sophisticated theory that conceptualises a process, action, or interaction situated within a particular time and context (Charmaz, 2014).

Constructivist grounded theory - A departure from classic grounded theory.

Following the proposal of classic grounded theory by Glaser and Strauss in 1967, constructivist grounded theory has integrated methodological advancements and addresses some of the criticisms of previous versions (Charmaz, 2011, 2014; Mills et al., 2006). This methodology adopts an abductive approach and has developed in recognition for the participant's social, historical, cultural, situational, and interactive context, and emphasises the researcher's subjectivity in social positions, thus demanding the researcher's reflexivity about the research process (Charmaz, 2006; 2014). Importantly, constructivist grounded theory acknowledges the role of the researcher as a co-constructor of the participant's reality and the need to reflect on how this might impact the research process (Charmaz, 2014; Mills et al., 2006), which is particularly important when interviewing children who are impressionable, vulnerable, and eager to please (Lyon, 2014). A further distinguishing feature of constructivist grounded theory is its resistance to mechanical applications of the method (characteristic of classic grounded theory), rather it allows for more flexibility in the process (Mills et al., 2006). For instance, classic grounded theory demands the researcher approaches the study of a particular phenomenon completely unencumbered by some form of prior knowledge or assumptions of that phenomenon (Glaser & Strauss, 1967). However, Charmaz argues this is neither practical nor necessary. In most instances, the researcher is likely to have some former awareness of a particular research topic and rather this can be beneficial to the study (Charmaz, 2014). Therefore, contrary to other grounded theorists, Charmaz encourages the researcher to develop an understanding of the context from which the data is being derived, or the world the participant is embedded within, thus enhancing the co-construction of data (Charmaz, 2006; 2014; Dunne, 2011).

The grounded theory process articulated by Charmaz (2006) is detailed in Figure 4. In this process, the researcher should remain open-minded and possess reasonably broad concepts of the phenomenon under investigation (Bryant & Charmaz, 2007). In most instances the researcher is likely to begin the process by conducting a broad literature review to understand the research topic (Charmaz, 2006; Dunne, 2011). Constructivist grounded theory uses theoretical sampling techniques, in a similar way to other grounded theory approaches. This enables the data to speak for itself, and for the researcher to follow up potential leads that might emerge from the data (McCall & Edwards, 2021; Tie et al., 2019). As new or novel concepts arise during the analysis, the researcher might choose to pursue these lines of inquiry by approaching individuals who are considered knowledgeable or experienced in these (McCall & Edwards, 2021; Tie et al., 2019). This technique also facilitates the process of determining when data saturation has occurred, and further sampling is not required (Aldiabat & Navenec, 2018; Charmaz, 2014). Here, it is important to distinguish between ‘the saturation of data’ and ‘the saturation of theoretical concepts’. In grounded theory, the notion of data saturation refers to the latter and, importantly, this occurs by definition or by claim by the researcher (Charmaz, 2014). That is, via constant comparison methods, data saturation occurs when there no new properties emerging during this process (Aldiabat & Navenec, 2018; Charmaz, 2014). Notably, grounded theory acknowledges these properties are likely to change over time and therefore, while all dimensions have been exhausted for now, and the decision to stop has been made, this is subject to change over time (Charmaz, 2014).

When conducting the initial coding of data, Charmaz (2014) suggests the researcher use a line-by-line coding process that focuses on applying *gerunds*, the doing or achieving words, to the data. Line-by-line coding is particularly effective for novice researchers in maintaining momentum in the coding process and is useful for comparing incidents (an action that leads to an outcome) simultaneously, rather than focusing on the most dramatic or obvious incidents within the data (Charmaz, 2014). Charmaz (2014) also considers line-by-line coding technique as a heuristic device for learning about the world under investigation. Simultaneous to line-by-line coding, the researcher uses *memoing* techniques selectively on codes that are significant and stand out (Charmaz, 2014; Tie et al., 2019). *Memoing* is an analytical technique for unpacking the meaning behind codes and elevating these beyond a simple description of the data (Charmaz, 2006, 2014; Tie et al., 2019). Similar to keeping a research diary reminiscent of other forms of qualitative research methodologies, the researcher is encouraged to draw out selectively significant codes and report their analytical and reflexive ‘musings’ on these (Charmaz, 2006; 2014, Stern, 2007; Tie et al., 2019). Like other versions of grounded theory, constant comparison methods (as discussed earlier), are central to constructivist grounded theory (McCall & Edwards, 2021; Tie et al., 2019). Following initial coding, axial coding of the data requires the researcher to compare the data against data (e.g., quotes against quotes, memos against memos, categories against categories) and thus elevate initial codes to the higher analytical level through asking analytic questions of these comparisons, such as the conditions under which these properties exist (Charmaz, 2006; 2014). It is through this process of constant comparisons that theory can be generated.

The process of grounded theory enables the generation of subjective middle to lower levels of theory (small ‘t’ theories), rather than those that constitute a generalisable ‘grand theory’ (big ‘T’ theories) (Groen et al., 2017). There are many variations of what theory is, however in the context of grounded theory, it is a set of well-developed and systematically interrelated categories which form a framework for explaining a phenomenon (Strauss & Corbin, 1994). Similarly, Charmaz (2014) considers theory to be an abstract understanding whereby theoretical concepts are linked together, and their relationships are observed, or present an understanding of the world in a more comprehensive and theoretical way. Therefore, by using this methodology, the present study anticipated findings would produce a sophisticated explanation of the processes, actions and interactions involved that affect children’s psychological wellbeing when a parent is diagnosed with cancer.

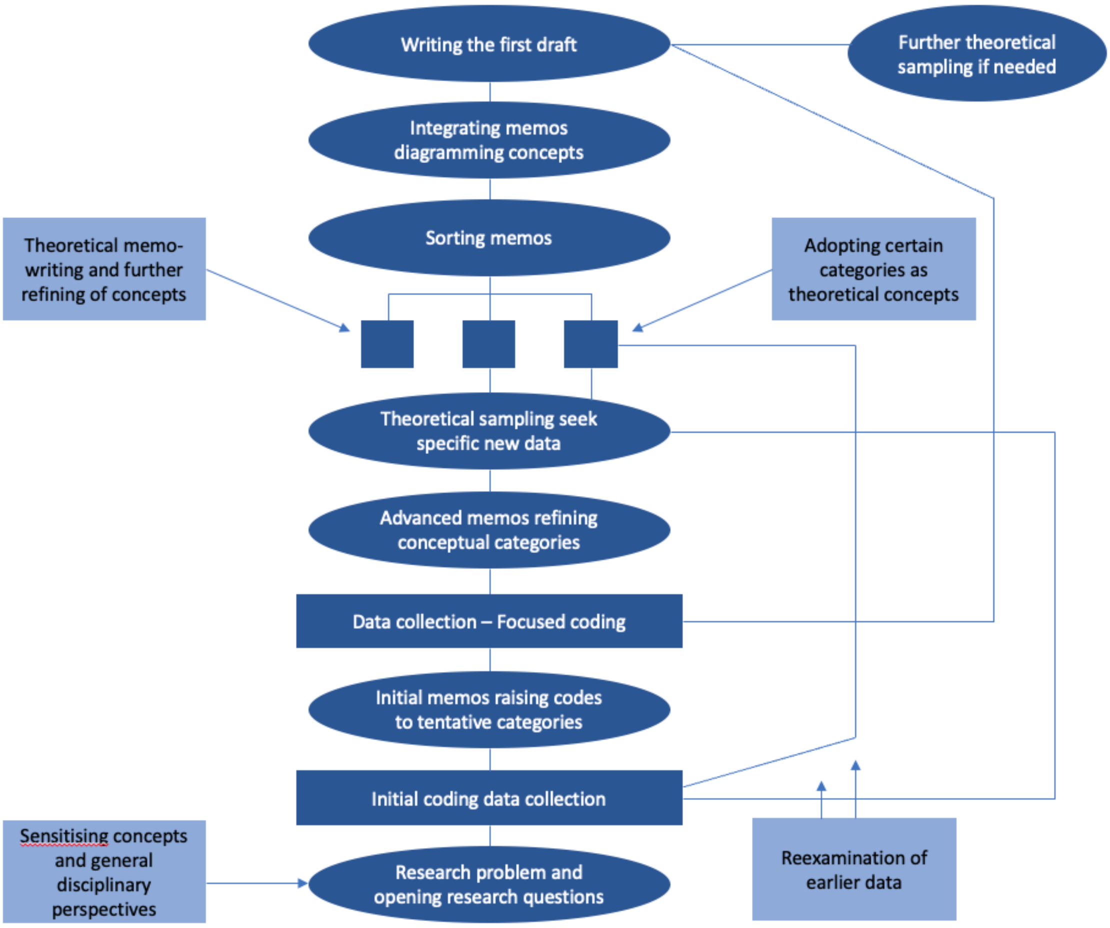

Figure 4. The grounded theory process. Adapted from Charmaz (2006; 2014).

Application of constructivist grounded theory in the present study.

Constructivist grounded theory forms an appropriate methodology for the present study as it is capable of generating a theory that conceptualises how cancer patients' children are affected when a parent is diagnosed with cancer. This addresses a key objective of this study, derived from the findings of the systematic review presented in chapter 2. Conclusions from this review indicated there is need for a theoretical model that explains the mechanisms involved which affect children's psychological wellbeing when a parent is diagnosed with cancer (Alexander et al., 2019). Importantly, this methodology acknowledges the individual agency and free will of participants (including children) who are capable of constructing new meanings and whose individual and collective interactions ongoingly determine their environment (Charmaz, 2014). It also enables an-depth interpretation of how children construct meaning through their own social interactions and is flexible enough to be used among diverse populations, including young children of various ages, where adaptive methodologies are necessary (Bennett, 2016; Zandt, 2017). Furthermore, it emphasises the co-construction of reality between the researcher and the participant (Charmaz, 2014). This process is necessary with children, whose varying cognitive capacity makes it difficult for them to comprehend and articulate their experiences when a parent is diagnosed with cancer (Alexander et al., 2020). Through co-construction the researcher and the child develop a shared and mutual meaning of the child's experiences, thus acknowledging the agency and expertise of the child in the construction of their own reality, while supporting their need to talk to adults who can field questions as they arise and assist with developing possible explanations (Gjems, 2011).

Methods

As stated at the end of Chapter Two, the research aims and objectives, and research questions of this study were as follows:

Research aims and objectives

The overall aim of this study was to explore how children are affected by their parents' cancer diagnosis, from the perspectives of children, parents, and health professionals and develop an explanatory model conceptualising the underlying mechanisms involved which influence how children are affected by their parents' cancer diagnosis.

The specific objectives of this study were to:

- Explore oncology health professionals' perspectives regarding how children are affected by their parents' cancer diagnosis.
- Explore parents (including patients and partners of patients) perspectives regarding how their ability to support their children is affected when a parent is diagnosed with cancer.
- Explore children's perspectives of how they are affected by their parents' cancer diagnosis.
- Propose a model conceptualising the underlying mechanisms involved which influence how children are affected by their parents' cancer diagnosis.

Research questions

The research questions posed to achieve the research aim and objectives were:

- How do oncology health professionals perceive patients' children are affected by their parents' cancer diagnosis?
- How do parents (including patients and partners of patients) perceive their ability to support their children is affected when a parent is diagnosed with cancer.
- How do children perceive they are affected by their parents' cancer diagnosis?

Research design

As detailed earlier in this chapter, this study adopted an integrated theoretical approach combining symbolic interactionism (Blumer, 1969) and Ecological Systems Theory (Bronfenbrenner, 1979), which has been used in previous child studies (e.g., Migliaccio & Raskauskas, 2015; Thornburg 2017). This approach was used as it accounts for the high level of influence children's social interactions and their environment have on their developmental outcomes. Informed by this theoretical approach, the methodology used in this study was constructivist grounded theory. This methodology enabled an in-depth, co-constructive exploration of participants' unique insight and experiences when a parent is diagnosed with cancer, additional to the development of a theoretical model conceptualising the mechanisms underlying how children are affected by this experience. Therefore, the methods offered by this methodology were considered appropriate to achieve the research aims and objectives and answer the proposed research questions.

Ethics approval and considerations

This research study was conducted in accordance with the guidelines outlined by the National Health and Medical Research Council's national statement ([NHMRC], 2007), and the Australian Psychological Society's code of ethics ([APS], 2007). Ethics approval was received from Sir Charles Gardiner Hospital's ethics committee, approval number: 12102016 (see Appendix C) and reciprocal approval from Curtin University's Human Research Committee. The following key ethical issues were considered in the development and conduction of this study:

1. The issue of beneficence is paramount in research, particularly when it involves vulnerable populations such as cancer patients and children. It was felt that the benefits of conducting this study outweighed the potential risks to participants, particularly given the paucity of empirical and clinical support currently available for patients' children. Developmental considerations were consistently undertaken across all phases of this study to ensure children's welfare was prioritised. Consultation with oncology health professionals and a clinical psychologist who was involved in the initial stages of development of this study, promoted the safeguarding of patients', parents', and children's wellbeing.
2. Informed voluntary consent was obtained for all participants through the provision of a participant information sheet and consent form prior to their interviews (see Appendix D). Children were also made fully aware that their participation was voluntary and that they may discontinue at any point without explanation or consequence. This was verbally explained to children by their parents and the researcher and outlined in a participant information sheet designed for children (which included other important study details), thus ensuring children were well informed prior to giving their verbal assent (see Appendix E).
3. While participants' identities were known to the primary researcher, as outlined in participant information sheets, participants' privacy was always respected and protected. Furthermore, any identifying data was excluded from publications resulting from this study. Data is currently stored electronically on a secured server and in a locked file at Curtin University. Information will be retained for a period of 7 years (adults) and 25 years (children), before being destroyed.
4. It was acknowledged that this study may evoke levels of worry and distress for some participants, particularly children, therefore, parents were provided with a list of current contactable local supports at the end of each interview (see Appendix F). Furthermore, if necessary and with permission from the participant (or parent in the case of children), the patient's cancer nurse coordinator was notified, however, this measure was not needed for any of the participants. This study was at all times conducted with the upmost respect for participants and their wellbeing was the primary consideration.

Participants

Key informants.

Children are highly embedded within their family system and other systems that are situated in their micro- and meso-systems, meaning these systems have a great influence on children's developmental outcomes (Bronfenbrenner, 2005; Malin et al., 2016). In the context of parental cancer, parents and health professionals have a profound influence on children's ability to cope and adjust to their parents' diagnosis (Dalton et al., 2019; Viser et al., 2006; Walczak et al., 2018). As such, they are crucial in understanding how children are affected by their parents' diagnosis. Furthermore, children are rarely heard in clinical and research settings, yet there is increasing awareness for the unique insight children provide about their experiences (Bradbury-Jones et al., 2018). Therefore, the primary aim of this study was to explore the perspectives of key informants, which included health professionals, parents/patients, and their children. Three qualitative studies were conducted with these key informants to achieve this aim.

Recruitment.

Participants comprising health professionals (*n* = 15), parents/patients (*n* = 11), and their children (5 to 17 years, *n* = 12), were initially recruited through a Comprehensive Cancer Centre at a metropolitan tertiary teaching hospital in Perth, Western Australia using purposive methods (i.e., driven by the study purpose or aim). Health professionals within the centre were approached via the contacts of the primary supervisor of this thesis and asked to advise potential participants of the details of this study. Fliers were also disseminated on bulletin boards situated in the centre and the hospital (see Appendix G). Potential participants meeting the proposed inclusion criteria (see Table 2) either contacted the primary researcher directly or were contacted (with permission) by the researcher, via email or phone. A mutually convenient time and location was arranged by the researcher and participant. Participants were advised that their involvement with the study was voluntary and provided with a participant information sheet and consent form prior to the interview. Parents were also provided the option of involving their children in the study. Interested children were provided a child-friendly participant information sheet which either they could read, or their parents could read to them before participating in the interview. On the day of the interview, children's verbal assent was received by the researcher additional to informed consent from parents on their children's behalf. All participants were given a participant demographic sheet to complete (see Appendix H) before their interviews. Parents completed children's details for them. Data analysis and recruitment occurred concurrently, meaning as new themes emerged, theoretical sampling was used to explore, verify, saturate, and expand these themes further by approaching participants who were considered to have knowledge and insight regarding novel themes (Charmaz, 2006; 2014). This process of recruitment, interviews, and data analysis continued until no new categories were emerging in the data indicating the saturation of theoretical concepts (Charmaz, 2014).

Table 2.

Participant Inclusion Criteria

Population	Inclusion criteria
HPs	• Must be experienced in providing health care to patients with cancer who have a child or adolescent (up to the age of 18 years) living at home.
Parents	• Must be a parent diagnosed with cancer or a parent whose partner has been diagnosed with cancer, at any stage of the cancer diagnosis. • Must have a child living with them aged 18 years or below.
Children	• Must be living at home with a parent who has been diagnosed with cancer. • Must be 18 years and under.

Interviews

Semi-structured, in-depth interviews were conducted with health professionals, parents, and children between April 2017 and June 2018. According to Charmaz (2014), pre-planned interview guides with open-ended questions enable the interviewer to focus on and be responsive to what the participant is saying, additional to promoting the participant's capacity to provide a rich and detailed description of their experiences. Interview guides focused on exploring key informants' perspectives regarding how children affected by their parents' cancer diagnosis and participants' unique experiences. Development of the interview schedules (see Appendix I) were guided by the research questions, a general literature review (see Chapter One), and findings from the systematic review (see Chapter Two).

Children's activity.

A novel approach was developed to assist children's interviews to aid with rapport and facilitate their capacity to articulate their responses to questions. This approach was informed by arts, drawing, and projective techniques used in participatory research to assess children's wellbeing (Stewart-Tufescu et al., 2019) and distress among vulnerable children, including those who are victims of sexual abuse (Cohen-Liebman et al.; Katz & Hershkowitz, 2009, Veltman & Browne, 2002) and war (Green & Denov, 2019; Miles, 2000). Furthermore, these techniques are appropriate and effective among children from different cultural backgrounds (Yang & Park, 2017). In this approach, children were provided with a collection of distractive age-appropriate toys to alleviate their sense of direct conversation which can be uncomfortable for children (Landreth, 2002; 2012). They were asked to draw a self-portrait alongside the researcher, during which the researcher asked questions about the child's parent's cancer diagnosis in addition to any worries and concerns they might have. These worries and concerns were written down on coloured post-it notes, and children were asked to position the post-it notes on their self-portrait relative to the level of worry they felt. The closer in proximity to the child's self-portrait, the more worry elicited by that concern. Please see Figure 5 for an example of a child's drawing featuring their reported worries and concerns. "My dogs dying", "people I care about dying" and "or animals [dying]" are the primary worries and concerns expressed by this child.

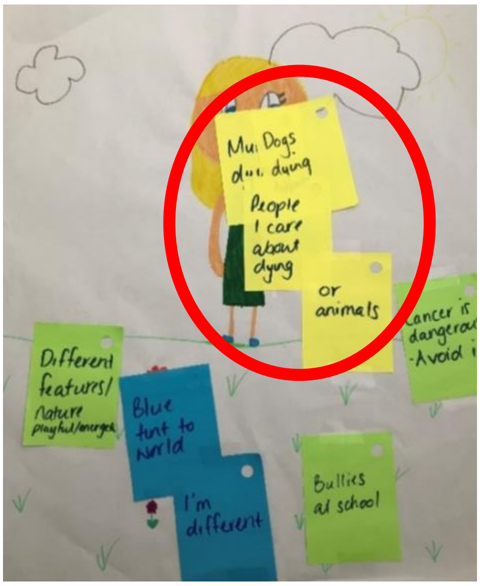

Figure 5: Child’s self-portrait and relative worries (Kayla (pseudonym); female: 10.5 years)

Procedure

Individual interviews with health professionals occurred either in person at their place of work or via a scheduled telephone call. Interviews with parents were conducted in the participant’s home, the University, temporary accommodation, place of work, or the tertiary hospital. Children were interviewed at the same location as parents, however, these interviews occurred separately to parents and parents were not present in the room at the time of the interview. As detailed earlier, informed consent was obtained from participants additional to verbal assent from children. At the end of each interview, all participants were provided the opportunity to add further comments, ask questions, and given a $15 gift voucher to reimburse them for their time. Parents were also provided with a list of current local contactable supports for children and thanked for their time. Observational notes and journaling immediately following interviews were used to record notable details regarding context and behaviours. Participant codes were used for health professionals’ and parents’ names and pseudonyms were used for children’s names, to ensure confidentiality and anonymity.

Data analysis

To ensure the analysis was conducted rigorously, guidelines and criteria outlined by Pope and Mays (Mays & Pope, 2000; Pope & Mays 2006) and Braun and Clarke (Braun & Clarke, 2006) were followed, including creating an audit trail of the methods and data analysis used and providing transparent and accurate reports of the research studies and findings. The Consolidated Criteria for Reporting Qualitative research guidelines ([COREQ] Tong, Sainsbury, & Craig, 2007) were also adhered to, to further promote study and reporting rigor. Interviews were digitally recorded (with consent) and transcribed verbatim. One child asked not to be recorded and this was respected. A detailed summary of this interview was documented immediately following completion of their interview and used in the analysis process. A confidentiality agreement was obtained from the transcription service used, to protect participant's privacy. Transcribed interviews were analysed using methods of constructivist grounded theory (Charmaz, 2006; 2014). Transcribed interviews were read through multiple times by the primary researcher, to establish familiarity with the data. Initial line-by-line coding of the first five transcripts for health professionals, parents, and children was conducted focusing on gerunds (actions and processes) to identify codes. Following this, data and codes were then transferred into Microsoft Excel to index the data into manageable chunks and develop preliminary themes. Transcripts were reviewed and discussed by the supervisory team and researcher, following an iterative process, so that themes could be refined. Agreed upon themes and the data were then transferred into NVivo12 where the remaining transcripts were coded. During this process, the researcher remained open to identifying further themes. Memoing techniques were also used to support themes in moving from the descriptive to the analytical level (Charmaz, 2014; Glaser, Strauss, & Strutzel, 1968).

Reflexivity.

Reflexivity in qualitative research is important for promoting rigor as it allows the researcher to scrutinise how their assumptions and values influence research outcomes (Alley et al., 2015). This is important for studies adopting constructivist grounded theory methods because central to this methodological process is the researcher's role as a co-constructor of the participant's responses (Charmaz, 2006; 2014). That is, the underlying motivations and experiences of the researcher are recognised to impact the participant's reality, and as such it important the researcher reflects on how this influences the research process (Charmaz, 2014; Mills et al., 2006).

The Researcher

In 2003 my younger sister, Zoe, was diagnosed with Acute Myeloid Leukemia (AML), an aggressive form of childhood leukemia that affects the blood and bone marrow. She was 14 years old at the time of her diagnosis and I, aged 17 years and having just graduated high school, had recently relocated from our regional hometown of Geraldton to Perth, the state capital which is approximately 5 hours driving distance away. I can still recall the phone call from my mum to advise she and my sister would be flying to Perth via the Royal Flying Doctor Service, as Zoe was unwell, and our family general practitioner had requested she undergo further testing. As there had been no obvious warning signs or presenting symptoms alluding to something more serious, the intensity of what was happening was bewildering.

I could sense the gravity of the situation, but with little information to go on, I could do nothing but wait anxiously for my mum and sister to arrive in Perth, and not let my thoughts escalate. The next few days were a whirlwind of testing, fear, and uncertainty. The word "cancer" was being mentioned in hushed tones, which only exacerbated my imagination. Cancer was a death sentence, right? Eventually, Zoe was diagnosed with AML and her year-long fight against cancer commenced, as did our family's struggles to continue with the realities and responsibilities of everyday living, while supporting a child with a cancer diagnosis. My mum was required to stop work and relocate to Perth to be with Zoe, who was placed in isolation at the children's hospital for much of her treatment, while my dad stayed in Geraldton to continue working to support our family. I frequented between the two locations, to be with my mum and sister, to maintain my own work and income, and to take care of our family home and support my dad whose work was quite physically and mentally taxing. Though my recollection of the details from that year are fading, the ongoing emotional, psychological, and physiological turmoil I experienced, remains with me every day.

When my sister died just before Christmas and her 16th birthday, I was broken. Not only because I had lost her, but the events of the past year had been debilitating. Witnessing her drawn out suffering, spending anxious days and nights by her hospital bedside, driving back and forth between Geraldton and Perth, and then waiting day by day for her death, took its toll on all of us. Our family was broken and would remain so for years to come. The ongoing guilt I still feel for the relief I felt when she died, and for the things I should have done differently ‘if I’d just known more’, continues to haunt me. I could never understand how someone so young could endure something so devastating, including the realisation of their own mortality.

The limited psychological help and communication my sister received to reconcile this knowledge and awareness of her fate, is still difficult for me to comprehend. Furthermore, the heartbreak and mental trauma she endured being separated from friends and family for a year, locked away in a clinical isolation room, and with little psychosocial support, adds to the sadness and guilt I feel. I wish I had understood and known more so that I could have alleviated some of her pain and distress. Perhaps I too would have benefitted from more intervention at various times during her diagnosis. As such, this life changing event has led me to study psychology and my current research pursuit. I recognised immense gaps in the extent to which hospital and healthcare systems provide psychosocial support for children with cancer, and children generally, and I now want to be part of developing that support.

CHAPTER 4

Study 2: The perceived effect of parental cancer on children still living at home: According to oncology health professionals[4]

Chapter Overview

This chapter consists of the first qualitative study proposed in this thesis. The purpose of this study was to explore health professionals' perceptions regarding how children are affected by their parents' cancer diagnosis. This was achieved by using methods of constructivist grounded theory and semi-structured interviews. This study has been published as a peer reviewed article, titled 'The perceived effect of parental cancer on children still living at home: According to oncology health professionals', in the *European Journal of Cancer Care,* a multidisciplinary journal for promoting comprehensive cancer care provision. The article reports on the detailed analysis of responses from 15 health professionals working in oncology. Findings from this article can be used to address current limitations observed in parental cancer research regarding the experiences and insight afforded by health professionals concerning how cancer patients' children are affected by their parents' diagnosis. Furthermore, findings may inform oncological clinical and healthcare practices to ensure cancer patients' children are appropriately supported.

What this study adds to the literature:

- Systemic and clinical barriers mean children are not being detected by health professionals and consequently they are not receiving the timely support they

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[4] This chapter has been published in the *European Journal of Cancer Care* and can be found online here.

require to promote their coping and adjustment to their parents' cancer diagnosis.

- Psychosocial and sociodemographic factors render some children more at risk of going undetected and unsupported, however, little is known about these factors.
- Health professionals do not feel they are adequately trained or experienced to know how to support patients' children and therefore are unlikely to approach children or raise the topic of children with patients.

Clinical recommendations from this study include:

- There is need for a standardised, ongoing, comprehensive screening process and referral pathways to be implemented as a part of routine care, to detect patients' children and ensure they are engaged with the appropriate support services and resources.
- Development of health professionals' communication skills with parents and children and improved developmental knowledge of children, is required to improve health professionals' confidence and likeliness to support patients' children.
- Health professionals would benefit from improved awareness and knowledge for supporting the needs of diverse populations, including those from different cultural and religious backgrounds.

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ORIGINAL ARTICLE

The perceived effect of parental cancer on children still living at home: According to oncology health professionals

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Abstract

Objective: How children are affected by their parent's diagnosis is limited in the literature, and children are typically not considered in current clinical practice. Despite suggestion that the patient's oncology team are well placed to support their children, this is yet to be sufficiently explored. This study aimed to explore how oncology healthcare professionals (HPs) perceive children are affected by a parent's diagnosis of cancer.

Methods: This qualitative study was informed by principles of grounded theory and embedded within a social constructivist framework. 15 health professionals working in oncology were interviewed using a semi-structured format. Data were analysed using methods of constant comparison.

Results: From the perspective of HPs, when a parent is diagnosed with cancer, their dependent children are rendered invisible. Factors within the (a) clinical healthcare system and (b) the families' psychosocial context were identified, which contribute to the invisibility of children.

Conclusion: HPs are well-placed to facilitate an entry point into the healthcare system for patients' children; however, this is not occurring due to children's lack of visibility. Clinical and psychosocial barriers need to be addressed to ensure HPs are visibly aware of all children and thus able to appropriately support, intervene or refer on.

KEYWORDS
children, oncology health professionals, parental cancer, psychosocial, qualitative research

1 | INTRODUCTION

In Australia, the projected estimate for new cancer cases among adults aged 25–49 years is 16,715, accounting for 8.66% of all new cancer cases in 2019 (AIHW, 2019). Reported 5-year survival rates suggest patients and their families are living longer with the impact of a cancer diagnosis (Werner-Lin & Biank, 2009). This younger cohort is likely to be in the workplace or studying, and many will have dependent children living at home (Semple & McCaughan, 2013; Werner-Lin & Biank, 2009). In Australia, there are currently no population data regarding the prevalence and characteristics of children living with parental cancer. However, a longitudinal study conducted in Western Australia (WA) reported that 0.28% of children experienced a parent's cancer diagnosis in 2015 (Martini, Morris, Jackson, & Ohan, 2019).

1.1 | Impact on families

Following a cancer diagnosis, patients and their families are likely to experience disruptions to their normal routines, strains to relationships, changes in roles and responsibilities, financial pressures and difficulty maintaining adequate social supports (Buchbinder, Longhofer, & McCue, 2009; Kim, Baker, Spillers, & Wellisch, 2006; Northouse et al., 2007). Parents often struggle to maintain normal parenting roles and responsibilities, and children endeavour to cope with their parent's cancer and family changes, while remaining on track developmentally (Huizinga et al., 2011; Semple & McCance, 2010; Turner et al., 2007). Despite reports of positive growth in families following a cancer diagnosis (Kissil, Niño, Jacobs, Davey, & Tubbs, 2010; Wong, Cavanaugh, Macleamy, Sojourner-Nelson, & Koopman, 2009), evidence suggests that a range of maladaptive psychosocial, emotional and behavioural responses may emerge in children (Huizinga et al., 2011; Krattenmacher et al., 2012; Morris, Turnbull, Preen, Zajac, & Martini, 2018).

1.2 | Children are invisible and have no support

Patients worry about their children's psychosocial well-being and development (Turner et al., 2007) and may also be physically and emotionally unavailable to support their children due to their own needs (Moore, Rauch, Baer, Pirl, & Muriel, 2015). Yet, much of the literature appears to focus on supporting the patient and their spouse with little consideration for children (Grabiak, Bender, & Puskar, 2007; Huizinga et al., 2011). Children often support themselves (Helseth & Ulfsaet, 2003), preferring not to speak to adults and feel isolated from friends (Tucker, Sugerman, & Zelov, 2013). Children also remain undetected in clinical and health systems and are typically not on the radar of the patient's oncological team (Arber & Odelius, 2018; Niemelä, Repo, Wahlberg, Hakko, & Räsänen, 2012). A recent systematic review reported current intervention research is limited and generally of poor methodological quality, and what is presently available does not appear to support children effectively (Alexander, O'Connor, Rees, & Halkett, 2019).

1.3 | Health professionals

Health professionals (HPs) within clinical settings are well positioned to identify and provide psychosocial support to patients' children (Dencker et al., 2019). However, HPs often avoid initiating discussion with patients regarding children, preferring their patient to raise the subject (Dencker et al., 2019; Turner et al., 2009). Reported reasons include HPs not having the skills to support children and fears of making the situation worse (Arber & Odelius, 2018; Franklin, Arber, Reed, & Ream, 2019; Niemelä, Väisänen, Marshall, Hakko, & Räsänen, 2010). Patients wait for their oncologist or other team member to instigate discussion (Dencker et al., 2019), and children do not recognise hospitals as a place to seek emotional support (Finch & Gibson, 2009).

1.3.1 | Aim

This study aimed to explore how oncology HPs perceive children are affected by a parent's diagnosis of cancer.

2 | METHODS

2.1 | Design

It is acknowledged this descriptive study does not form a pure grounded theory approach. Rather it has been informed by principles from Glaser and Strauss's (1967) grounded theory methods and Charmaz' (2014) adaptation of this method, which emphasises a constructivist perspective and highlights the co-constructed realities between the participant and the researcher. Given the infancy and complexity of the research topic in the present study, this approach is appropriate as it yields a theoretical conceptualisation of the phenomena under investigation, rather than a simple description of events.

Hospital and University ethics approval was received for this study in the ethics approval of a broader study it was part of, which involved interviews with HPs, patients/parents and children. This paper focuses on HPs' perspectives.

2.2 | Participants

15 HPs were recruited using theoretical sampling, a method that allows the researcher to sample participants and analyse data concurrently. Participants who had knowledge of, or experience with cancer patients' dependent children (up to 18 years) were invited to participate. As new themes emerged, theoretical sampling was used to explore these further, by approaching participants considered to have insight regarding novel themes. Participants were predominantly women (80%) with a mean age of 51.46 (±10.5) years. Years of relevant experience with cancer patients and their children ranged from 2 months to more than 30 years. Roles were varied (see Table 1).

2.3 | Interviews

Semi-structured interviews lasting approximately 45 min ($M = 43$ (±22), range: 14.32–82.52) were conducted, which enabled topic consistency while allowing the interviewer to pursue alternative lines of enquiry and derive further explanation and examples of topics where relevant. It also enabled participants to focus on their own perspectives without being restricted. The interview schedule (see Table 2) was guided by the research question, a literature review and findings from a systematic review (Alexander et al., 2019). The aim of these interviews was to explore how HPs perceive patients' children are affected by their parent's cancer diagnosis. Interviews took place in person in the participant's place of work ($n = 8$) or via a scheduled telephone call ($n = 7$). Observational notes and/or reflexive journaling were used depending on the how the interview was conducted (i.e. in person or via telephone) to provide a more detailed description of context and behaviours, and to ensure rigour and quality (Nagy & Viney, 1994).

2.4 | Procedure

Participants were initially recruited through a Comprehensive Cancer Centre at a metropolitan tertiary teaching hospital. Fliers were posted on bulletin boards within the hospital and centre. HPs within the Centre were also approached via one of the researcher's contacts and asked to advise potential participants of the study, who were then emailed or telephoned to scope their interest in participating by the researcher. A mutually convenient time and location were then arranged between the researcher and participant. Participation was voluntary. Participants were provided with an information sheet and signed a consent form prior to the interview.

TABLE 1 Participant demographics

Health professionals	Number of participants	$n = 15$
Age	Range Mean age (SD)	31–71 years 51.21 (±10.14) years
Gender	Women Male	80% 20%
Role	Cancer Nurse Coordinator	$n = 3$
	Psychosocial support worker or other allied health worker	$n = 6$
	Nurse practitioner	$n = 1$
	Clinical/oncological specialist	$n = 3$
	Clinical psychologist/psychiatrist	$n = 2$
Years of relevant experience	≤10 years	$n = 5$
	≤20 years	$n = 4$
	≤30 years	$n = 4$
	>30 years	$n = 2$

2.5 | Data analysis

Interviews were digitally recorded and transcribed verbatim. Data collected were analysed using constant comparison (Charmaz, 2006) to identify themes. To ensure the analysis was conducted carefully and rigorously, guidelines and criteria outlined by Mays and Pope (2006) and Braun and Clarke (2006) were followed. Transcripts were read through several times by the first author to ensure strong familiarity with the data. Initial line by line coding of the first five transcripts focusing on gerunds (actions and processes) was used to develop an understanding of what was happening in the data (Charmaz, 2006).

Data and codes were then transferred into Microsoft Excel to index the data into manageable chunks and elevate codes to form the basis of preliminary themes. In an iterative process, transcripts were then reviewed by the other members of the research team and themes were discussed and refined. Once a consensus regarding themes was reached, data and preliminary themes were transferred to NVivo 12 where the remaining transcripts were coded accordingly, while remaining open to identifying further themes. *Memoing* techniques were applied throughout the data analysis process, to maintain connection between the codes and the data itself and to encourage themes to move from the descriptive to the analytical level (Charmaz, 2014; Glaser, Strauss, & Strutzel, 1968).

3 | FINDINGS

The overarching finding was that visibility of patients' children is generally poor among HPs. Children's visibility relies on HPs being aware of the presence of patients' children and other psychosocial aspects related to this. These HPs are crucial in terms of whether children receive timely support or not. Factors in the patients' clinical environment and the families' psychosocial environment emerged as central themes that effect children's visibility in healthcare systems.

TABLE 2 Topic guide for qualitative interviews

Number	Question	Prompts
1	Tell me about your contact and involvement with patients' children?	*Experiences*
2	What do children come in for? What do they talk about with you?	*What is life like for these children?* *What is going on for them?*
3	How do you feel patients' children are affected by their parents' cancer?	
4	What do you think would help patients and their children?	
5	What are your concerns for the wellbeing of patients' children?	
6	What supports do you feel children need to adjust to their parent's cancer diagnosis and treatment?	*Are these supports available* *What supports are available?*
7	Are patients' children supported in clinical practice?	
8	How might staff be assisted in providing support for children?	*How would you suggest these children could be better supported and assisted?*
9	Is there anything else you would like to say?	

3.1 | Clinical factors that affect children's visibility in the healthcare system

According to HPs, there are factors in the patients' clinical environment, predominantly the hospital setting, which affects the visibility of patients' children. Three subthemes of this are discussed.

3.1.1 | Clinical environment

According to HPs, the clinical environments where patients are being diagnosed and treated are not appropriate settings for detecting or psychosocially supporting children, as one HP indicated, *"I don't know if they sit in the clinical setting … We're only seeing a snapshot of children"* (HP3). The patient is the primary focus of the oncology team and staff are unlikely to come across patients' children in these settings. Moreover, there is a disconnection between HPs from different health backgrounds that leads to confusion regarding whose responsibility it is to support and detect children. Consequently, the likelihood of children being overlooked is high as HPs assume others are screening for children. *"If everyone is thinking the social worker will make a referral, it's leaving it to the social worker, but they don't automatically see every patient. So, there's a lot that can be overlooked"* (HP11).

3.1.2 | Children are not detected as part of routine screening or referral processes

Identifying patients' children relies on whether HPs ask their patients about children, or for patients to initiate this conversation, as there is no routine screening process in place that prompts HPs to do this as a standardised part of care. *"There's no process. If someone is referred to a social worker for assistance, it would be only if someone has picked up on this, but who is picking up on it?"* (HP2). Some HPs reported conducting their own screening process, however, conveyed concern that this does not occur routinely, and therefore, children are likely to be overlooked.

> That's [screening] something we initiate ourselves. We normally try to get as much information about their social life and their family life as we can and then if they tell us they do have kids, then we explore.
>
> (HP5)

Also, there are currently no processes for appropriately referring children to other services. The services that are available rely on referral to identify and engage children. As one psychosocial support worker for children indicated,

> We are relying on nurses and people in the healthcare profession to remember about [service]. It is not usually part of their standardised screening, but ultimately it would be good for it to be so that more referrals can come to [service].
>
> (HP11)

3.1.3 | HPs' knowledge and inexperience with children

The lack of clinical referral often stemmed from HPs' uncertainty regarding services and how to access them. One HP stated, *"Probably there are a number of supports out there, but it's having access to them and working out who can have access to those different things"* (HP7). Another HP stated, *"There's lots of pamphlets around but people just hand them out like you hand out a bag of lollies, [and] sometimes you don't know exactly what those services are doing"* (HP5). HPs often reported that their limited experiences with patients' children contributed to their apprehension to have conversations with patients about their children. They were concerned they would do more harm than good. *"I'm not experienced in child psychology. I really am fearful that I would be doing an injustice opening up a conversation that I didn't have the tools to complete"* (HP3). Most HPs felt they needed to be better informed and educated to engage with patients' children. *"More education and knowing the usual things of being able to signpost people to where help can be sought"* (HP7).

3.2 | The families' psychosocial factors that affect children's visibility in the healthcare system

According to HPs, factors in the families' psychosocial environments also affect the visibility of patients' children. Three subthemes around this are discussed.

3.2.1 | Parents want to protect their children

Parents play a role in the lack of their children's visibility. According to HPs, most parents want to protect their children by keeping them away from the clinical settings, *"I feel a lot of the time they shield the kids, so they don't bring them in"* (HP4), which reduces children's visibility. Parents' preferences to keep their children away from clinical settings limit the capacity for HPs and children to seek out each other. Parents are also unwilling to disclose vital information to children such as that they are sick or that their death is imminent. This is often due to a sense of protecting their children and, in some instances, themselves. As one HP recounted,

> I've been in the situation where Mum or Dad is actually dying, imminently dying within an hour or so, and the other parent pops out and I get the message, can you tell the children that they're [parent] dying.
>
> (HP13)

Religious and cultural factors

Protecting children was also relayed to religious and cultural backgrounds. HPs are limited by what parents are willing to disclose, which is sometimes shaped by families' cultural and religious beliefs. For example, one HP said,

> There are some cultural differences which impact on children's knowledge about what their parents are going through… people from Asian countries and some parts of eastern Europe don't tell their children about what's happening.
>
> (HP1)

Cultural and religious differences can result in some patients and their children being under-supported or not accepting assistance and guidance. In these instances, HPs found it difficult to balance cultural and religious sensitivity with getting children the necessary help and support. As one HP said,

> The grandparents held strong religious beliefs and believed that prayer was going to save her. They gave the child and her and the husband a lot of mixed messages, so much so that she wasn't even sure she was dying in the days before she died… So, they didn't prepare the child.
>
> (HP6)

3.2.2 | Parents' availability to support their children

HPs recognised the emotional and physical challenges parents experience after a cancer diagnosis, and how this affects their capacity to attend to their children's ongoing needs.

> Children and young adolescents look to their parents for support and emotionally their [parents] are struggling. The impact on the child is huge…who helps them go forward?
>
> (HP8)

Of paramount concern to HPs were children who were most likely to go undetected, for reasons such as their parent's limited psychological capacity to advocate for support for their children, or their lack of physical capability to access resources. HPs reported there are some parents with a comorbidity of serious mental and/or physical health problems alongside their cancer diagnosis, and their children are more likely to go undetected.

> There are a small number of parents who have serious mental health problems, schizophrenia etc. and who also have cancer and those children are exponentially more vulnerable because their parent's contact with cancer services is often quite fragmented and so the kids don't get tapped in to the basic resources'.
>
> (HP6)

3.2.3 | Children are reluctant to talk about what they are thinking and feeling

Children's reliance on parents often means they are reluctant to talk to other adults, including HPs.

> "With the ones that are reluctant to talk, it is a lot more challenging and I feel that even when I am trying to build more of a rapport with them and sneakily get some questions in here and there, it's not always going to go well.
>
> (HP12)

HPs observed that children also conceal their thoughts and feelings from parents to protect their parents' feelings because they are concerned for how this will affect them, *"Sometimes there are ones that have never really spoken about it because they're afraid of upsetting their parent or whatever the circumstance might be"* (HP12). Consequently, parents assume their children are coping and do not seek out professional support. Even when children are approached, they are not always ready to talk, as it can be confronting and overwhelming for them. HPs indicated communication needs to be child centric, that is, it needs to be timely and ongoing to accommodate children's processing of information and developing cognitive sophistication. One HP provided the following insight:

> Sometimes they [children] will process it through play therapy, but not be able to articulate it verbally how they're feeling. Then, once the diagnosis has got to a safer distance, they might be able to engage in some verbal dialogue, or as they're getting a little bit older they might be in a position to articulate and want to revisit what's happened.
>
> (HP9)

4 | DISCUSSION

This qualitative study investigated how oncology HPs perceive children are affected by their parent's cancer diagnosis. Similar to previous literature, HPs in this study reported patients' children are generally invisible in the healthcare system and consequently go undetected and without professional help (Dencker et al., 2019; Semple & McCance, 2010). Our study also identified various clinical and psychosocial factors which, according to HPs, affects children's level of visibility. The presence of these factors influences whether children are detected by HPs and appropriately referred on within healthcare systems.

Our findings indicate children are reluctant to talk to HPs and they lack the cognitive-verbal competence to describe their needs and concerns. Concerns regarding communication are commonly reported in the parental cancer literature, with previous studies highlighting the importance of open, timely and age-appropriate discussion that encourages children to share their experiences and minimises possible confusion or misinterpretation of information (see review by Ellis, Wakefield, Antill, Burns, & Patterson, 2017). HPs in our study also reported children tend to avoid direct conversations as they find it confronting and overwhelming. This mirrors developmental literature which suggests face-to-face conversation can facilitate an automatic barrier between adults and children; and assumes children's capacity to communicate at an adult level (Landreth, 2002; O'Reilly & Dolan, 2016). Rather, congruent with suggestions from HPs in the present study, child health communication literature recommends practitioners use child friendly and playful approaches that build trust and incorporate hands on materials, repetition and reinforcement (Bennett, 2016; Zandt & Barrett, 2017).

According to HPs, their capacity to support patients' children is largely governed by the parents' attitudes and wishes, with parents presenting as children's gatekeepers and the level of disclosure children receive. This supports findings in the literature that parents want to protect their children and facilitate as much normalcy and distance from the cancer diagnosis as possible (Franklin et al., 2019; Sølvi Helseth & Ulfsæt, 2005; Shands, Lewis, & Zahlis, 2000). Also, parents often underestimate children's distress due to their own coping needs (Lewis, Case y, Brandt, Shands, & Zahlis, 2006). Consistent with our findings, other studies indicate that parent's intentions to protect their children often compromise the provision of necessary, timely, open and ongoing discussion with children which consequently contributes to their ongoing anxiety and distress-related symptoms (Finch & Gibson, 2009; Helseth & Ulfsæt, 2005; Semple & McCaughan, 2013).

Our study also highlighted children who are at greater risk of going undetected and unsupported are those whose parent's psychosocial and socio-demographic situation is likely to render them less aware of their children's needs and/or with less capacity to access support. There appears to be little literature regarding how these factors may affect patients' children and the barriers and enablers to detecting and engaging them. Similarly, our findings around the challenges associated with families' religious and cultural barriers when supporting children are also an under investigated area in the parental cancer and general healthcare literature. This creates a tension whereby HPs are required to be respectful of patients' preferences, while also providing best care practices to all patients and their children (Department of Health Western Australia, 2008; National Institute for Health Care Excellence, 2019).

The culture and skill set of hospital staff appear to be inadequate to support patients' children as they are not the focus of the patient's oncology team. This resonates with extant cancer literature that reports the primary concern of HPs is the patient and their disease management and treatment, and their access to patients' children is generally limited (Huizinga et al., 2011; Niemelä et al., 2010). We also found it was common for HPs to have limited knowledge and experience with children and this was likely to affect their confidence to approach patients' children or have conversations with patients about their children. This supports earlier studies that found staff are encumbered by their lack of knowledge and expertise regarding children (Dencker et al., 2019; Grant, Sangha, Lister, & Wiseman, 2016; Turner et al., 2009) and require more education and experience to improve their confidence in supporting patients' children (Semple & McCaughan, 2019; Turner et al., 2009).

A further factor contributing to children's limited visibility is HPs missed opportunities to identify patients' children. Reasons for this included the absence of a routinely implemented standardised psychosocial screening process. Previous studies conducted in other healthcare systems, such as Germany, also report similar systemic issues (Ernst et al., 2013; Romer et al., 2007). Our findings highlight that even when questions around patients' children are asked and at-risk children are detected, there are insufficient resources in place to direct HPs with referring patients' children on. Therefore, despite the presence and implementation of international, national, and state guidelines and frameworks such as the Psycho-Oncology Model of Care, which states that 'patients' families and carers, should have equitable access to psychosocial care' (Department of Health Western Australia, 2008), children are not routinely considered.

4.1 | Limitations

It is important these reported findings are interpreted within the proposed limitations of this study. There was a gender bias towards women participants. A recent study by Sinclair et al. (2019) reported a similar bias and suggested this reflects the gendered nature of this industry (i.e. support professions). There are national data to support this, for example the Australian Bureau of Statistics (2018) reported 89% of nurses are women. While it is possible male HPs may have yielded different perspectives, it was observed that responses from participating male HPs were similar to those from womens. Furthermore, participants were recruited from one state (WA) within Australia. While some of the findings reported in the present study are similar to those reported in other studies, it is acknowledged that the nature of some of our findings might be specific to WA, and therefore may not be applicable to, or representative of, other states within the country or internationally.

4.2 | Practical implications

It is customary for oncology HPs to support patients with little consideration for their dependent children, which is largely due to children's limited visibility in healthcare systems. This is often a great source of distress for patients and leaves their children vulnerable to the burden of living with parental cancer without appropriate support or intervention. The findings from this study can be used to inform future guidelines and practice in psycho-oncology, through stressing the need for an ongoing comprehensive psychosocial screening process to be implemented as a part of routine care. Our findings also support current recommendations for further education for HPs to improve their confidence with approaching patients' children and discussions around the subject of children. This may also serve to mitigate parents' gatekeeping and children's reluctance to talk to HPs. Our findings can be used to promote better staff awareness of diverse populations and families.

5 | CONCLUSION

HPs within the patient's oncological healthcare team are well placed to detect and refer children who at risk (Forrest, Plumb, Ziebland, & Stein, 2006). However, the findings of this study indicate this is not routinely occurring. Rather, from the perspective of HPs, when a parent is diagnosed with cancer their children are rendered invisible. There are factors within the patients' clinical and psychosocial environment, that affect the visibility (or lack thereof) of patients' children and their capacity to reach necessary supports and resources. These findings further our understanding regarding how children are affected by their parent's cancer diagnosis and highlight areas where the visibility of children can be improved thus to promote early detection by HPs and subsequently children's likeliness to receive timely intervention and support.

CONFLICT OF INTEREST

All authors declare no conflict of interest.

ETHICS APPROVAL

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CHAPTER 5 Study 3: Supporting parents with cancer: Practical factors which challenge nurturing care[5]

Chapter Overview

This chapter consists of the second qualitative study proposed in this thesis. The purpose of this study was to explore how children are affected when a parent is diagnosed with cancer from the perspectives of parents. This was achieved by using methods of constructivist grounded theory and semi-structured interviews. The study reports on the detailed analysis of responses from 11 parents (including patients and partners of patients). Findings from this study can be used to address current limitations observed in parental cancer research regarding the support needs of parents when a parent is diagnosed with cancer, thus enabling parents to tend to their children's physical and psychosocial needs. Furthermore, findings may inform the comprehensive and holistic psycho-oncological care of patients in clinical and healthcare systems by ensuring their children's needs are also being met.

What this study adds to the literature:

- Parents are overwhelmed by the practical aspects associated with the cancer diagnosis, which challenges their capacity to provide timely and ongoing support to their children.
- Diagnosis is a particularly crucial time where parents require practical support as there is much occurring at this time.

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[5] This chapter has been prepared for submission to the Journal of Psychosocial Oncology.

- The family's psychosocial characteristics, such as being regionally or rurally located, issue unique challenges for some families.
- The dissemination of medical and healthcare information overwhelms and confuses parents, making it difficult for them to make informed decisions and appropriately communicate with their children about the diagnosis

Clinical recommendations from this study include:

- Improving health professionals' awareness and knowledge of the unique challenges which encumber patients who are also parents of young dependent children.
- Addressing systemic issues within hospital and clinical settings and integrating clinical and community care to support parents with navigating the practical challenges associated with a cancer diagnosis. For example, a family support worker or social worker who can lessen the burden on parents by assisting them with these challenges (e.g., maintaining children's school and education), from diagnosis onwards.
- Providing education and support for health professionals to ensure the diagnosis and other medical and healthcare information is more appropriately and effectively disseminated to parents.

Supporting parents with cancer: Practical factors which challenge nurturing care.

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Declarations

Consent to participate: Informed consent was obtained from all individual participants included in the study.

Consent for publication: The authors affirm that human research participants provided informed consent for publication of their data.

Availability of data and material: Data is available upon request.

Code availability: Not applicable

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Abstract

Introduction: Cancer patients' children are vulnerable to psychosocial and behavioural issues. Parents commonly report concern for supporting children and their need for health professional assistance. This study aimed to explore how parents' ability to support children is affected when a parent is diagnosed with cancer.

Methods: Informed by methods of grounded theory and embedded within a social constructivist framework, 11 patients and spouses were interviewed using a semi-structured format. Responses were analysed using methods of constant comparison.

Results: Practical challenges overwhelm parents and impacts their capacity to support children. Four overarching themes were identified: i) Adjusting to the cancer diagnosis; ii) Keeping life going; iii) Supporting the patient's physical and cognitive changes; and iv) Balancing parenting workloads and identities.

Conclusions: Early and tailorable intervention that addresses these practical challenges may promote parent's ability to support their children, improve parent's and children's psychological wellbeing and coping, and mitigate children's maladjustment.

Introduction

The five-year survival rates among Australian patients aged 25 to 49 years are rising (AIHW, 2019), meaning patients and families are living longer with the impact of a cancer diagnosis (Werner-Lin & Biank, 2009). For these adults, parenting forms a primary component of their identity and is often overlooked by their multidisciplinary oncological team (Muriel et al., 2012). While there is currently no national population data regarding the prevalence and characteristics of children living with parental cancer, a longitudinal study conducted in Western Australia (WA) reported that 0.28% of children experienced a parent's cancer diagnosis in 2015 (Martini et al., 2019).

A cancer diagnosis presents a chronic and pervasive stressor, and families experience conflict within roles and responsibilities, difficulty accessing social and support networks, and financial burden (Buchbinder et al., 2009). These factors are exacerbated by the emotional, physical, and cognitive impact the disease and treatment have on the patient (Greening, 1992; Manne et al., 2007). Children must also endeavour to cope with their parent's cancer diagnosis while remaining on track developmentally (Huizinga et al., 2011), with evidence indicating they are vulnerable to various psychosocial, emotional, and behavioural problems, including symptoms of Post-Traumatic Stress Disorder, anxiety, and depression (Foran-Tuller et al., 2012; Walczak et al., 2018).

It appears there are few resources to effectively support patients and their children and to mitigate the potential for long term adverse outcomes. Current approaches to healthcare recognise the need for optimal levels of psycho-oncological care for patients and their families, which includes children (Porter-Steele et al., 2017). However, patients' children remain invisible in clinical systems and to healthcare professionals (HPs) (Alexander et al., 2020). Recent reviews indicate current interventions are generally of poor methodological quality and limited effectiveness (Alexander et al., 2019; Ohan et al., 2020). Despite parents' reported distress regarding their children's wellbeing and desire for input from HPs (Dencker et al., 2019; Golsäter et al., 2019), there are barriers (e.g., limited time and experience) that challenge or discourage HPs from engaging with patients about their children or make it difficult for HPs to access or approach patients' children (Alexander et al., 2020; Dencker et al., 2017; Tafjord, 2021).

Extant literature indicates parents often feel too distressed, symptomatic, or pressured and this is likely to affect their capacity to support their children (Park et al., 2016b; Rauch & Muriel, 2004). Parents' concerns regarding parenting are present from the onset of diagnosis, and parents reporting higher levels of concern are likely to experience greater psychological distress (Muriel et al., 2012). Parents are offered little help to support their children, which can exacerbate levels of stress and impact the parent-child relationship (Babore et al., 2019). Parents are uncertain regarding how to talk to and support their children and evidence suggests parents often underestimate their children's need for information (Helseth & Ulfsæt, 2005; Semple & McCance, 2010). Yet, relationship and communication quality within families is important for preventing adverse longer-term consequences among children (Howell et al., 2016).

Aim

When a parent has cancer, children prefer to seek support from their parents, and HPs find it difficult to intervene and engage with children. However, parents' capacity to provide children with this support is challenged and parents report heightened levels of distress related to this. This study aimed to explore how parents' ability to support their children is affected when a parent is diagnosed with cancer.

Methods

Design

This qualitative study was informed by principles of grounded theory positioned within a social constructivist framework (Charmaz, 2014), which emphasises each individual's constructed meaning of the world and unique experiences. This method is appropriate given the complexity of the research topic; rather than a simple description of events it gives voice to the participant and yields an interpretive rendering of their experiences.

Hospital and University ethics approval was received for this study in the approval of a broader study which explored children's experiences of a parent's cancer diagnosis and involved interviews with HPs, parents, and children. This article focuses on parents' perspectives.

Participant recruitment

Purposive and theoretical sampling techniques were used to enable concurrent participant recruitment and data analysis. Participants were recruited through a tertiary teaching hospital in metropolitan Perth, Western Australia (WA). Nurses within the hospital were approached via one of the researchers' pre-existing networks and asked to advise potential participants of the prospective study. Fliers advising study details and purpose were posted on hospital bulletin boards. Inclusion criteria stipulated the person be a parent with a cancer diagnosis or a parent whose partner has been diagnosed with cancer and have a child living with them aged 18 years or below. Interested participants contacted the primary researcher. An appropriate time and location for the interview was arranged. As new themes emerged, theoretical sampling was used to explore these further, by approaching participants considered to have insight regarding novel themes.

Interviews

Semi-structured interviews were used (Charmaz, 2014), which allowed the interviewer to maintain topic consistency while also promoting the pursuance of alternative lines of enquiry. It also enabled participants to focus on their own unrestricted perspectives. The interview schedule (Table 1) was guided by the research question, a general literature review, and findings from a systematic review (Alexander et al., 2019). Interview questions focused on exploring how parents perceived their children were affected by their parent's cancer diagnosis.

Table 1.

Topic Guide for Qualitative Interviews

Number	Question	Prompts
1	Can you tell me a bit about who is in your family?	*Such as who is in your family? Do you have any pets?*
2	What activities do you and your family enjoy doing together?	
3	Has any of this changed since your/your partner's diagnosis?	
4	Tell me about your cancer diagnosis	

5	What are the key challenges you have faced since your/your partner's diagnosis?	
6	Do you feel okay talking to your children about your/your partner's cancer and any changes?	*[If not]* Okay, why is that? *How have you talked to your children?*
7	How do you think your child/ren has/have been affected by your/your partner's cancer? How do you feel your child/ren has/have coped with your/your partner's cancer diagnosis?	
8	Have you noticed any other changes in your child's/children's behavior?	
9	What, if any, worries or concerns do you have for your child/ren and their coping with your/your partner's cancer?	
10	Do you feel confident and comfortable with supporting and assisting your child/ren to cope with your/your partner's cancer, and any problems or issues that might arise?	*What support have you had?*
11	Is there anything that might make you feel more comfortable to do this?	
12	What are the main challenges you face with supporting your child(ren)?	*Is there anything else you would like to say?*

Data collection

Individual interviews took place in participants' homes (*n* = 4), University (*n* = 3), temporary accommodation (*n* = 2), place of work (n = 1), or hospital (*n* = 1). Participants were provided participant information sheets and informed consent was gained prior to the interview. This time was also used to establish a rapport with participants prior to commencing interviews. The average duration for interviews was approximately 46 minutes (M = 45.88 (±10.05), range: 27.36 – 73.14).

Observational notes and journaling were used to record context and behaviours, and for future reference. Theoretical sampling techniques enabled data saturation to be determined when there were no new themes emerging in the collected data (Aldiabat & Le Navenec, 2018). It was also decided at this point that no repeat interviews would be necessary.

Data analysis

Interviews were digitally recorded and transcribed verbatim. Collected data were analysed using methods of constant comparison (Charmaz, 2006) to identify themes. Guidelines and criteria outlined by Pope and Mays (2006) and Braun and Clarke (2006) were also followed to ensure analysis rigor. Familiarity with the data was established by the first author through several readings of transcripts. Initial line by line coding of the first five transcripts focusing on gerunds, was used to develop codes (Charmaz, 2006) which were then transferred into Microsoft Excel to index the data into manageable chunks and elevate these to form the basis of preliminary themes. Transcripts were also reviewed by the research team and themes were discussed and refined in an iterative process. Agreed upon themes were then transferred to NVivo 12 where the remaining transcripts were coded, while remaining open to identifying further themes. Memoing techniques were also employed to support themes to be moved from the descriptive to the analytical level (Charmaz, 2014; Glaser, Strauss, & Strutzel, 1968). Consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong, Sainsbury, & Craig, 2007) were adhered to further promote study and reporting rigor.

Findings

All 11 patients and spouses of patients (herein collectively referred to as parents) who contacted the researcher, completed their interviews between April 2017 and June 2018. Participants' mean age was 39.7 (±7.44) years, with 90% (*n* = 10) of all parent participants being female (Table 2). 45% of participants were parents without a cancer diagnosis (n = 5).

Table 2.

Demographics

Parents	Number of participants	n = 11
Age	Range	28 – 52 years
	Mean age (SD)	39.7 (±7.44) years
Gender	Female	91%* or *n* = 10
	Male	9%* or *n* = 1
Health status	Patient	5
	Partner	6
Marital status	Married	9
	Separated / Divorced	1
	Widowed	1
Number of children**	1 child	4
	2 children	4
	3 children	2
Age range of children**		1 to 15 years
Cancer type (primary)**	Bowel cancer	2
	Brain	1
	Breast	1
	Burkitts lymphoma	1
	Lymphoma	1
	Melanoma	1
	Non-Hodgkin's Lymphoma B cell	1
	Lung	1
	Oral	1
Stage** (at time of interview)	II	3
	III	1
	IV	3
	Not reported / remission / deceased	3
Ethnicity	Australian	82% or *n* = 9
	Indonesian	9% or *n* = 1
	Malaysian	9% or *n* = 1
Education	Postgraduate	4
	Tertiary	5
	Other	2

*Rounded to nearest whole %

** One family was represented by two parents, therefore the responses to these questions were adjusted to account for overrepresentation

Practical challenges

Following a parent's cancer diagnosis appears to be a crucial time where there is much upheaval and parents experience many practical challenges that overwhelm them and affect their parenting roles and capacity to support to their children. Four themes were identified: I) Adjusting to the cancer diagnosis, II) Keeping life going, II) Supporting patients' physical and cognitive changes and, IV) Changing workloads and responsibilities.

Adjusting to the cancer diagnosis

For most parents, receiving their cancer diagnosis was shocking and unexpected and they felt overwhelmed.

"They thought it was an ovarian cyst. When they opened up they realised it was cancer that had spread from the bowel. So, they removed part of my bowel, my right ovary, and some lymph nodes. When I came to, they told me the news and I was pretty shocked" (Parent 9).

There was much that happened at the time of diagnosis, including the dissemination of large amounts of information. Parents felt overwhelmed through needing to take in this information and then make imminent informed, life changing decisions.

"The information comes so fast and quick; you're making 'informed decisions'… how can you make 'informed decisions' when information comes in that thick and fast and in things that we know nothing about". (Parent 2).

"We're sitting there and we're having to decide on the spot whether or not he's going to have further treatment". (Parent 7).

Navigating the hospital and health care systems was also challenging, time consuming, and demoralising.

"If you have to phone to change an appointment, you don't go to a receptionist. You go to some third party who may or may not be able to change an appointment or answer a question, so it's absolutely hopeless whatever that system is, so we don't even bother" (Parent 1)

Factors such as the family's dynamics and sociodemographics exacerbated the level of overwhelmingness parents experienced. For example, some families lived in regional and rural areas of WA, however, could only receive cancer treatment and support in one metropolitan area (Perth), therefore requiring their immediate relocation.

"I rang the Leukaemia Foundation; started packing the house. I changed the kids' school; I got all that done within that week because the next week we had to be in Perth." (Parent5).

The uncertain nature of the cancer diagnosis further challenged parents' ability to plan for their family's future and promote stability.

"There's always something that comes up. We've tried to plan for the best, expect the worst." (Parent 3)

Moreover, the ongoing and chronic nature of a cancer diagnosis left parents feeling mentally and physically exhausted.

"It could be a year. It could be 20 years. We're not even thinking about that, we just keep going." (Parent 1)

Keeping life going

A significant challenge perceived by most parents was how to integrate the cancer diagnosis into the context of the family dynamics. Everyday life and responsibilities still needed to be navigated while also dealing with the diagnosis and treatment.

"Mostly we get on with life. We've got school tomorrow. We've got to make sandwiches…" (Parent 9)

Maintaining their children's school engagement and academic performance was challenging. Though, parents who communicated their cancer diagnosis to the schools, generally reported their school was supportive and accommodating.

"The high school was good with [child]. They had psychologists she could talk to." (Parent 4)

Also, while parents would have liked their children to continue their sports, hobbies, and other social activities, these often were restricted due to diagnosis and treatment demands.

"We had them enrolled in gymnastics and basketball… everything was just a bit full on when I got sick… we decided to strip back all the things we were doing with the kids" (Parent 3).

Financially, parents had to make decisions regarding lifestyle and future, to accommodate the loss of household income and treatment costs. Despite the demands of the disease and treatment, patients often had to continue to work, or one parent bore the sole financial burden in addition to caregiving.

"I was in hysterics because financially the only position that we could manage was if [patient] was down here [Perth] by himself." (Parent 5).

"I [patient] needed to continue working, we had to prioritise what we could and couldn't do." (Parent 1).

Supporting the patient's physical and cognitive changes

Supporting the ongoing and often unanticipated physical and cognitive changes, and other side effects that occurred due to the disease and treatment, was generally taxing for both parents.

"While he's neutropenic you can eat an apple, but you've got to wash your hands; wash your face before you kiss or hug dad; you've just got to be really conscious. Lots of extra handwashing. We have good hygiene, but I'm just seeing bugs everywhere. It's cleaning constantly." (Parent 2).

This particularly impacted families of out-patients where their clinical and support needs were attended to by the other (healthy) parent.

"Just being really aware of [healthy parent] and how much he's going to have to take on." (Parent 7).

Parents also found it difficult to balance children's exposure to these changes.

"We've tried to avoid having her there [hospital]. She'll come to an MRI because that's an easy scan. Things where there's not likely to be anything awful she'll see. When he's in hospital, we don't take her in. We also don't want her to hear something that she takes the wrong way. We want to filter what she hears through us first." (Parent 1).

The patient's response to treatment was often unpredictable, so changes were commonly made to treatment plans. This challenged parents' capacity to prepare themselves and their children while maintaining stability and continuity. Also, the patient's hospitalisation (sometimes unanticipated) had a significant impact on the family.

"He [patient] got very sick and ended up in the high intensity unit because they had to call a code blue, which was probably a bit of a shock seeing dad so sick in hospital, and for [child] - that was probably the hardest week for him. It was stressful for all of us; me trying to still work, going into hospital every night" (Parent 4).

Balancing parenting workloads and identities

Generally, the patient's decline in health and wellbeing led to an increased workload and changed responsibilities for the other parent.

"She's [wife] taken a lot of the load of stuff that I would have dealt with before. She deals with most of the financial stuff now; just trying to not get me stressed out so I can concentrate on getting better" (Parent 4).

There was often much upheaval to the healthy parents' attention and responsibilities. They felt forced to choose between being a parent to their children or being the patient's advocate and assisting them with navigating their treatment decisions and the healthcare system, while providing the emotional and physical support they required.

"To manage the illness - I felt I was put in the position of having to choose between parenting and supporting (patient) through to the end of his life." (Parent 10).

Alternatively, the patient often felt divided between prioritising their health, the impact of the disease and the demands of treatment, with their responsibilities of being a good parent and partner.

"I still don't think they [children] understand how tired and sick I am. Sometimes it gets overwhelming. They get quite demanding… so trying to explain to them but trying not to make them feel like I'm getting cross at them." (Parent 1).

This act of balancing parenting workloads and identities was evident long after remission. For example, often there were profound psychological, mental, and physical impacts of the cancer diagnosis and treatment which continued to affect the cancer survivor.

"The children pick up on my stress. They certainly pick up on his stress. My five-year-old was wetting the bed and the more [patient] got sleep deprived because he was getting up in the middle of the night changing sheets, the less tolerant of it he became and that becomes like a negative cycle." (Parent 9).

Discussion

When a parent is diagnosed with cancer, practical challenges identified made it difficult for parents to support their children, which contributed to feelings of worry and distress regarding how their children were coping. The period following diagnosis was a crucial time where parents felt they required better support, particularly with practical aspects of receiving a cancer diagnosis and what happens next. Extant literature focusses on parents’ need for help supporting children’s emotional and psychological needs, such as adequate communication and information provision for children (Walczak et al., 2018). Our findings suggest the practical challenges identified in this study are equally as concerning for parents, as they impact parents’ capacity to provide nurturing care for children. These practical challenges may also contribute to issues reported in previous studies, which highlight parent difficulties to accurately discern children’s needs (Helseth & Ulfsæt, 2005; Lewis et al., 2015; Semple & McCance, 2010; Visser et al., 2007), and providing timely and ongoing discussion necessary to promote children’s coping (Ellis et al., 2017). Therefore, prioritising support and resources for the practical challenges parents face at the time of disgnosis appears neccessary to mitigate parent distress and position them to address their children’s needs.

At the time of diagnosis parents reported their state of shock and confusion, yet this was also a time when many things were happening, including the dissemination of a significant amount of medical/health information which was difficult for most (including those with good health literacy) to understand. Navigating this information occupied much of parents’ time and was mentally taxing, rendering parents less able to be responsive to children’s physical and emotional needs, or as previous research has reported, misinterpret children’s needs and adjustment (Lewis et al., 2006, 2015). The pressure on parents to make immediate, life changing decisions that yielded significant consequences for their family and the patient’s treatment outcomes, further challenged their capacity to support children’s needs. Hence, parents felt left behind at this point. While extant literature shows that time of diagnosis is crucial and distressing for parents (Ghofrani et al., 2019; Moore & Rauch, 2006), this remains an unaddressed gap in research and clinical practice.

Maintaining children’s daily living and basic needs, including ensuring an adequate diet, presented further challenges and distress for parents following diagnosis or during treatment. Often children’s schooling, sporting, and social activities were compromised due to the time and financial demands imposed on overwhelmed parents. Literature also shows parents experience difficulty ensuring their children’s basic and higher order needs (e.g., food, safety, psychosocial support) and there is significant disruption in family daily living routines which can have detrimental effects on children’s wellbeing (Ghofrani et al., 2019; Sigal et al., 2003). For some parents in this study, daily struggles were exacerbated by sociodemographic factors, such as living in regional and rural areas of WA, where relocation and/or extensive travel to receive treatment and support presented further barriers. This is consistent with regional and rural health research that evidences greater disadvantage and poorer health outcomes for families living outside metropolitan areas (Australian Bureau of Statistics [ABS], 2016; Australian Institute of Health and Wellbeing [AIHW], 2019). Improving parents’ capacity to support children’s needs and continuity of daily routines would likely mitigate parent distress and promote parent’s and children’s wellbeing. This might be in the form of providing parents with or directing them to existing community and clinical resources, such as a family support worker, who could assist parents with the practical challenges associated with the cancer diagnosis.

Physical and cognitive changes in patients due to the disease and treatment, was often confronting and unavoidable for children, particularly those whose parent was an out-patient and children were constantly exposed to this. Parents wanted to protect their children while balancing their needs for adequate information provision. Being an out-patient also made it increasingly difficult for patients to have time away from child related demands and balance their priorities of getting well and being a good parent. Children also reported their need for time away from the cancer diagnosis. While informal interventions such as *Children’s Lives Include Moments of Bravery (CLIMB*) (Shallcross et al., 2016) and *The On Belay Program*, (Tucker et al., 2013) have considered this and proved effective at a qualitative level, they are yet to be evaluated with greater methodological rigor (Alexander et al., 2019; Ohan et al., 2020). The chronic and unpredictable nature of cancer also makes it difficult for parents to foster stability and continuity for children, to appropriately prepare them for possible changes, and to make unrevised plans. Despite evidence for the detrimental impact uncertainty yields on children (Gazendam-Donofrio et al., 2009), and the challenges associated with being an out-patient (Ernst et al., 2013) there seem few recommendations regarding how these challenges might be mitigated. Protecting children from constant exposure to the effects of a cancer diagnosis and fostering separation for both parents and children, is a much needed area of support and intervention.

Parents often struggled with balancing their multiple roles and identities, which is commonly reported in the literature (Dencker et al., 2019; Northouse et al., 2012; Piil et al., 2015). For patients, the impact of the disease and treatment often diminished their capacity to be both mentally and physically available, and their focus oscillated between being a parent and being a patient. This led to increased workloads and responsibilities for partners, who were also advocates for patients' needs. Partners were torn between needing to provide emotional support and physical care for patients, while also supporting themselves and children. The detrimental impact role confusion and balancing workloads and responsibilities has on parents' wellbeing and the parent-child relationship, have been reported in previous studies (Elmberger et al., 2008; Golsäter et al., 2019; Götze et al., 2017; Muriel, 2012). Parents who experience more parenting concerns are also likely to experience greater psychological distress (Kim et al., 2006). Yet, children's health and functioning are linked to parents welbeing, hence children are likely to suffer alongside parents (Park et al., 2016a; Rauch & Muriel, 2004). There is evidence to suggest psychosocial factors such as social support, relationship satisfaction, and employment might have mitigating effects on parents' psychological distress (Götze et al.). Therefore, interventions or support aimed at improving these psychosocial factors among parents, may be considered.

Limitations

These findings must be interpreted within the limitations of this study. There was a gender bias toward mothers, which is common in parental cancer literature (Tavares et al., 2018). It is possible fathers may have yielded different perspectives, and future studies should consider exploring their perspectives. Participants were recruited through opt in methods and predominantly through cancer support services and centres, which likely produced a sample of participants with a higher level of psychological awareness about their situation and are more considered about their children's needs. Again, this factor is reported in similar studies (Park et al., 2016a).

Practical implications

Findings from this study can inform guidelines and practice in psycho-oncology and cancer care and treatment, through improving HPs awareness of the challenges encountered by patients' who are also parents of dependent children. Several practical challenges are identified in this study, such as addressing how the cancer diagnosis is given; supporting families' domestic and professional workloads and responsibilities; consulting and liaising with children's schools and extracurricular activities to maintain continuity; and assisting with symptom management, particularly for out-patients. Addressing these challenges would mitigate some of the pressure that overwhelms parents and promote parents' awareness and responsiveness to their children's needs. This support needs to consider systemic issues within the healthcare and hospital settings and integrate both clinical and community care. For example, a family support worker or social worker who can assist families with the practical challenges outlined, would be one such multidimensional approach.

Conclusion

This study has highlighted practical challenges that overwhelm parents, particularly at diagnosis, which impacted parent's psychological wellbeing and effected their responsiveness to children's needs. Systemic changes in healthcare and hospital settings in addition to clinical and community supports, with an emphasis on addressing unique barriers for rurally and remotely located families, are required to assist parents practically and enable parents to support their children. Ultimately, this is likely to foster improved psychological wellbeing for parent's and children and mitigate the potential for long term adverse outcomes among cancer patients' children.

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CHAPTER 6 Study 4: The psychosocial effect of parental cancer: Qualitative interviews with patients' dependent children[6]

Chapter Overview

This chapter consists of the thrid qualitative study proposed in this thesis. The purpose of this study was to explore children's perceptions regarding how they are affected by their parents' cancer diagnosis. This was achieved by using methods of constructivist grounded theory and semi-structured interviews. A novel developmentally tailored approach was also used to support interviews. The study reports on the detailed analysis of responses from 12 children aged 5 to 17 years. Findings from this study can be used to address current limitations observed in parental cancer research regarding how children are affected by their parents' cancer diagnosis, including the factors which influence their coping and adjustment. Furthermore, findings may inform future psycho-oncological intervention and clinical support for children by determining where children are positioned within clinical and healthcare settings to receive support and identifying what children's support needs are.

What this study adds to the literature:

- Cancer patients' children experience heightened levels of worry and distress at the time of diagnosis, and this continues to effect some children's psychosocial wellbeing past their parents' remission and/or bereavement.
- Children feel disconnected from their available support networks, including parents who are often unavailable or pre-occupied, extended family and friends who are difficult to access and perceived unlikely to understand, and

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[6] This chapter has been prepared for submission to the journal, Qualitative Health Research.

health professionals who they do not consider for psychosocial and emotional support.

- Children need help with comprehending their parents' cancer diagnosis and their associated complex thoughts and emotions, which impacts their capacity to effectively communicate with parents and other adults.

Clinical recommendations from this study include:

- Providing intervention, from diagnosis onwards, to mitigate children's ongoing worry and distress and lessen the potential for long-term psychosocial and emotional vulnerabilities.
- Developing and implementing a clinical resource which enables children and healthcare professionals to communicate more effectively. Such a resource might consider using the novel approach adopted in this study.
- Addressing clinical and systemic barriers to improve children's capacity to seek out health professionals for psychosocial and emotional support, and conversely enabling health professionals to detect patients' children and refer them on to the appropriate supports and resources.

The psychosocial effect of parental cancer: Qualitative interviews with patients' dependent children

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Declarations

Consent to participate: Informed consent was obtained from all individual participants included in the study.

Consent for publication: The authors affirm that human research participants provided informed consent for publication of their data.

Availability of data and material: Data is available upon request.

Code availability: Not applicable

Authors' contributions: All authors contributed to the study conception and design. Material preparation, data collection, and analysis were performed by E. Alexander, M. O'Connor and G. K. B. Halkett. The first draft of the manuscript was written by E. Alexander and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Abstract

Background: Children living with parental cancer are at an increased risk for various psychosocial, emotional, and behavioural problems. However, research regarding how children are affected by their parent's diagnosis is still developing and patients' children are typically invisible in clinical practice. This study aimed to investigate how children are affected by their parent's cancer diagnosis, from children's perspectives.

Methods: Informed by methods of grounded theory and embedded within a social constructivist framework, twelve children (ranging from 5 to 17 years) living with a parent with cancer were interviewed using a semi-structured format assisted by a novel approach derived from play and art based developmental literature.

Results: Findings indicate patients' children are constantly worried and distressed, and there are barriers that can be overcome to mitigate this. Four overarching themes were identified: I) Feeling worried and distressed; II) Comprehending their parent's cancer diagnosis; III) Being disconnected from their supports; and IV) Needing someone to talk to.

Conclusions: Children experience considerable levels of ongoing worry and distress when a parent is diagnosed with cancer, and have difficulties comprehending and articulating this. They also feel a level of disconnection from their usual support systems (e.g., parents) and are limited regarding who they can seek out and talk to. Mitigating children's ongoing worries and distress by promoting the availability and accessibility of parents and other supports to children, and reducing communication barriers between children and adults, should be a primary focus of psycho-oncology research and practice.

Introduction

The five-year survival rates among Australian cancer patients aged 25 to 49 years are rising (Australian Institute of Health and Welfare, 2019), meaning that patients and their families are living longer with the impact of a cancer diagnosis (Werner-Lin & Biank, 2009). Global research indicates many in this age range will be supporting dependent children while also coping with their diagnosis (Syse et al., 2012; Weaver et al., 2010), presenting a major challenge for this cohort. In Australia, there are currently no population data regarding the prevalence and characteristics of children living with parental cancer. However, a longitudinal study conducted in Western Australia, reported that between 1982 and 2015, 25,901 (approximately 24%) children (0-11 years) experienced a parent's diagnosis of cancer (Martini et al., 2019).

When a parent is diagnosed with cancer, families are likely to experience disruptions to routines, relationship strains, changes in roles and responsibilities, financial pressures, and difficulty maintaining adequate social supports (Buchbinder et al., 2009; Kim et al., 2006; Northouse et al., 2007; Semple & McCaughan, 2013). Families with dependent children face additional challenges, as parents report heightened levels of concern around how to appropriately support children, including apprehension about communication (Dencker et al., 2019; Shands & Lewis, 2020). Children are also endeavouring to cope with, and adjust to, their parent's cancer diagnosis and resultant family changes, while remaining on track developmentally (Huizinga et al., 2011; Morris et al., 2019; Ohan et al., 2020; Phillips & Lewis, 2015). Literature indicates factors such as age, gender, cancer stage, pre-existing comorbidities, parent's marital status and psychological health are likely to influence how children are affected (Huizinga et al., 2010; Jeppesen et al., 2016; Morris et al., 2018).

How children cope when a parent has cancer is an area of increasing research interest (Faccio et al., 2018; Morris et al., 2019). While some studies report resilience building and the potential for post-traumatic growth among cancer patients' children (Phillips & Lewis, 2015; Walczak et al., 2018), there is evidence to suggest the overall adjustment and emotional wellbeing of patients' children is negatively affected and children are at risk of various maladaptive psychosocial, emotional, and behavioural stress responses such as somatic complaints, separation anxiety, levels of distress, confusion, rumination, worry, and intrusive thoughts (Morris et al., 2018;

Walczak et al., 2018). For some children, these symptoms are likely to dissipate over time, however, there is evidence to indicate other children remain vulnerable to ongoing long-term problems, including self-injury and post-traumatic stress symptoms (Bylund-Grenklo et al., 2016; Stoppelbein et al., 2006). This vulnerability may be associated with the level of disruption children experience in the initial stages following diagnosis (Visser et al., 2007).

Research indicates cancer patients' children prefer to be supported and informed by their parents (Phillips & Prezio, 2016). Yet, a recent study found parents are often overwhelmed by the cancer diagnosis (Alexander et al. in review), and find it challenging to foster conversations with children and distinguish what is typical developmental behaviour from indications their child is struggling to adjust (Pholsena, 2009). Parents tend also to wait for health professionals to broach the topic of children due to the tension between being in the patient role and the parental role, and the emotional challenges when discussing their children (Dencker et al., 2019; Detmar et al., 2000). Health professionals are unlikely to raise questions about children with their patients (Dencker et al., 2019; Detmar et al., 2000) as they are typically inexperienced and have limited knowledge regarding children in families affected by cancer, and children are not visible or considered in adult clinical settings (Alexander et al., 2020).

Alongside this, intervention research continues to focus on parent-proxy reports regarding the effectiveness of interventions among patients' children (Alexander et al., 2019; Ellis et al., 2017), despite several studies highlighting that discrepancies are common between parents' accounts and children's (Huizinga et al., 2010; Lewis et al., 2015; Lewis et al., 2006). Recent reviews further indicate current programs and interventions are not effective in mitigating children's various psychosocial and behavioural outcomes, including depression and anxiety (Alexander et al., 2019; Ohan et al., 2020; Walczak et al., 2018). However, qualitative findings regarding interventions and programs available for patients' children support their feasibility and acceptability, indicating there is a voracity for interventions among parents and children (Alexander et al., 2019; Ohan et al., 2020).

The conflicting findings reported in the literature suggest there are gaps regarding how children are affected by their parent's cancer diagnosis and how they can be best supported. This study aimed to investigate children's perspectives of how they are affected by their parents' cancer diagnosis.

Methods

Ethics approval was received by Sir Charles Gairdner Hospital HREC and Curtin University HREC, for the current study, in the approval of a broader study exploring how children are impacted by parental cancer, and involved interviews with health professionals (Alexander et al., 2020), patients/parents (Alexander et al., in review), and children. This article focuses on children's perspectives.

Design

This study was informed by principles of grounded theory and was positioned within a social constructivist framework (Charmaz, 2014). This approach emphasizes each individual's constructed meaning of the world and unique experiences. This method was considered appropriate given the complexity of the research topic. Rather than a simple description of events, this approach promotes a theoretical conceptualization of the phenomenon under investigation.

Participant recruitment

Parents and patients (herein collectively referred to as parents) were recruited for interviews (Alexander et al., in review) and their children were also given the option to be interviewed. Recruitment took place at a tertiary teaching hospital in metropolitan Perth, Western Australia (WA) using convenience and snowballing sampling. One researcher's (MOC) pre-existing networks were used to approach hospital nurses who were asked to advise potential parents/patients of the prospective study. Fliers were also displayed on hospital bulletin boards. Inclusion criteria for parents/patients stipulated they must be a parent who had been diagnosed with cancer or a parent whose partner had been diagnosed with cancer, and that they had a child living with them aged 18 years or below. Interested parents contacted the primary researcher (EA) directly and a mutually convenient time and location for the interview was arranged. Children's interviews were conducted independently of their parents. As new themes emerged, theoretical sampling was used to explore these further by approaching participants considered to have insight regarding novel themes. Recruitment, interviews, and analysis continued until data saturation was achieved- that is, data was considered rich and detailed, and no new categories were emerging (Corbin & Strauss, 2008).

Participants

12 children were interviewed between April 2017 to June 2018. 58% of participating children were female with a mean age of 9.2 (± 3.5) years (see Table 1). Most children were from an Australian background (75%) and spoke English as their first language. All children were attending school, ranging from pre-primary to year 11. 6 children from 3 different families, were siblings and participated in the study. There was an equal number of mothers and fathers who had been diagnosed with cancer. Cancer type varied, including bowel, brain, breast, lymphoma, melanoma, lung and oral.

Table 1.

Demographics

Children	Number of participants	n = 12
Age	Range	5 – 17 years
	Mean age (SD)	9.46 (±3.43) years
Gender	Female	58% or *n* = 7
	Male	42% or *n* = 5
Cultural background	Australian	75% or *n* = 9
	Indonesian	17% or *n* = 2
	Malaysian	8% or *n* = 1
Parent with cancer	Mother	50% or *n* = 6*
	Father	50% or *n* = 6*
Parent's primary cancer diagnosis**	Bowel cancer	2
	Brain	1
	Breast	1
	Burkitt's lymphoma	1
	Lymphoma	1
	Melanoma	1
	Non-Hodgkin's Lymphoma B cell	1
	Lung	1
	Oral	1
Stage**(at time of interview)	II	3
	III	1
	IV	3
	Not reported / remission / deceased	3

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* *n* = 3 sets of siblings (*n* = 7 participants); siblings' parent with cancer was counted multiple times

** total number of patients included in the study was *n* = 10 (for further details regarding parents and patients, see Alexander et al., in review)

Interviews

Semi-structured interviews were used to enable the primary researcher and interviewer (EA, female, PhD candidate and experienced interviewer) to maintain topic consistency while also promoting alternative lines of enquiry, further explanation, and examples of topics where relevant. This also enabled the children to provide their own unrestricted perspectives. Interview questions focused on exploring how children perceived they were affected by their parent's cancer diagnosis. The interview schedule (see Table 2) was guided by the research question, a general literature review, and findings from a systematic review (Alexander et al., 2019). Interviews spanned approximately 38 minutes (m = 37.13, SD = 21.77).

Children's activity

A novel approach was developed and used during the interviews to facilitate children's capacity to articulate their responses to interview questions. This was influenced by arts, drawing, and projective techniques which are used in participatory research to assess children's wellbeing (Stewart-Tufescu et al., 2019) and distress among vulnerable child populations such as those affected by sexual abuse and war (Akesson et al., 2014; Cohen-Liebman, 1999; West, 1998). There is also evidence to suggest these techniques are efficacious among children from different cultural backgrounds (Yang & Park, 2017). Informed by principles of play therapy, children were also provided with a series of age-appropriate toys (e.g., spinners and mini footballs) by the interviewer to facilitate discussion and rapport and provide a distraction from direct, face to face conversations (Landreth, 2012). They were then asked if they would like to draw a self-portrait alongside the researcher who also drew one. During this drawing exercise, the interviewer proceeded to ask children questions around their parent's cancer diagnosis (see Table 2). Upon completion of the child's self-portrait, they were asked to list any worries and concerns including, but not limited to, those related to their parent's cancer diagnosis. As the child listed these, the interviewer wrote them down on coloured post-it notes. The child then positioned the post-it notes on their self-portrait. The more worry the child felt for each reported worry, the closer to the image of themselves it was placed. This can be observed in Figure 1, where one child demonstrated more worry about her mother's cancer recurrence than about her mother missing out on activities.

Table 2.

Topic Guide for Qualitative Interviews

Number	Question	Prompts
1	Can you tell me about your family?	Such as who is in your family? Do you have any pets?
2	What are the fun things your family enjoy doing together?	Have any of these things changed lately?
3	Is there anything that you worry about?	
4	I was hoping you could tell me a little bit about your [mum/dad]. Has [mum/dad] been sick lately?	
5	What do you call [mum's/dad's] sick/sickness?	
6	Tell me what you know about [mum's/dad's] sickness?	
7	If you have a question about [mum's/dad's] sickness, who do you ask or what do you do?	
8	Is mum and dad OK talking to you about [mum/dad] not being well?	*[If yes]* Tell me some of the things you talk about with mum and dad? *[If no]* Would you like to be able to talk to mum and dad about this more?
9	Are there more things you want to know about [mum's/dad's] sickness?	*[If yes]* Tell me what sort of things?
	What are some things you do to help you feel better about [mum/dad] not being well?	
	Has life been different since [mum/dad] found out [he/she] was not well?	*[If yes]* Tell me how it has been different?

Are things still the same with your friends, or have they changed?	*[If they have changed]* Tell me how they have changed?
Are things still the same at school, or have they changed?	*[If they have changed]* Tell me how they have changed?
Is there someone at school you prefer to talk to about [mum/dad] not being well?	*[If yes]* Tell me who this person is?
What makes you feel the happiest lately?	[Prompt] Activities? Things? Items? People?
And, what makes you feel unhappy or sad lately?	[Prompt] Activities? Things? Items? People?
If I asked you to do a special activity with mum or dad, and it could be any kind of activity, what would that special activity be?	
If you had a friend that found out their mum or dad was not well in a similar way to your [mum/dad], what would you do to help that friend?	
If you had 3 wishes, what would those wishes be?	

Data collection

Interviews were conducted in the participants' homes (*n* = 7), at Curtin University (*n* = 2), temporary accommodation (*n* = 2), or the tertiary hospital (*n* = 1). Participants' parents were provided with information sheets and written consent was gained. Also, children were provided developmentally appropriate information sheets and verbal assent was attained as per the National Statement on Ethical Conduct in Human Research chapter 4.2 (National Statement on Ethical Conduct in Human Research, 2007). Observational notes and journaling were used to record notable details regarding context and behaviours. All children completed their interview, however, 1 child refused to be recorded. A detailed summary was documented immediately following completion of their interview.

Data analysis

Interviews were digitally recorded and transcribed verbatim. Transcribed data were analysed using methods of constant comparison (Charmaz, 2006) to identify themes. Guidelines and criteria outlined by Pope and Mays (2006) and Braun and

Clarke (2006) were also followed to promote analysis rigor. Several readings of transcripts by the primary researcher enabled data familiarity. Initial line by line coding of the first five transcripts focusing on gerunds (actions and processes) was used to develop codes (Charmaz, 2006). These were then transferred into Microsoft Excel to index the data into manageable chunks and elevate these to form the basis of preliminary themes. Other members of the research team (MOC and GH) reviewed transcripts and themes were discussed and refined in an iterative process. Agreed upon themes were transferred to NVivo 12 where the remaining transcripts were coded, while remaining open to identifying further themes. Memoing techniques were also used to support themes to be moved from the descriptive to the analytical level (Charmaz, 2014; Glaser et al., 1968). The consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong et al., 2007) were used to promote study quality and reporting rigor.

Findings

Four overarching themes were identified: I) Feeling worried and distressed; II) Comprehending their parent's cancer diagnosis; III) Being disconnected from their supports; and IV) Needing someone to talk to. Talking about their parent's cancer diagnosis, was a subtheme identified under comprehending their parent's cancer diagnosis.

Feeling worried and distressed

During a parental diagnosis of cancer, children experienced ongoing distress and worry related to their parent's cancer diagnosis, alongside worries commonly experienced by children whose parent is not ill (e.g., peer relationships and academic performance). For example, patients' children were likely to harbour worry and concern regarding how their parent was coping, and possible outcomes including recurrence or death. This is illustrated in Figure 1, a drawing by a child who identified her mother's cancer recurrence and death, alongside missing out on school, as her three most prevalent worries.

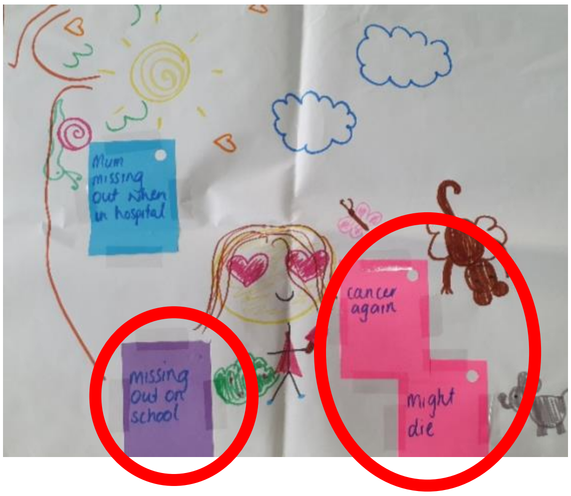

Figure 1. Child's self-portrait and relative worries (Indigo; female: 8 years)

Children's worries tended to be ongoing, and their level of intrusiveness appeared vulnerable to external circumstances such as whether the parent was in hospital or actively receiving treatment. For example, one child discussed her experience of an activity facilitated by an arts therapist who had been engaged by the family. In this activity, she was asked to report her worries and feelings. Her reiteration of this highlighted the chronic nature of her worry and the direct impact her mother's fluctuating health status had on her levels of happiness.

Child: "In my 'worries' I usually write about mummy's cancer and in the 'feelings' I usually write worried, happy, angry and frustrated".

Interviewer: "Is that how you generally feel?"

Child: "Yep".

Interviewer: "You feel worried and frustrated a lot of time?"

Child: "Yes".

Interviewer: "When do you feel happy?"

Child: "When mummy's okay and she's doing stuff" (Batari; female: 8.5 years)

Often this worry also generalized to other family members (including the healthy parent), friends, and pets.

"I worry about the dogs dying. I worry about mum dying. I worry about all of my family, really" (Kayla, female: 10 years). This participant also evidenced this as her most prevalent worry in her drawings, as observed in Figure 2.

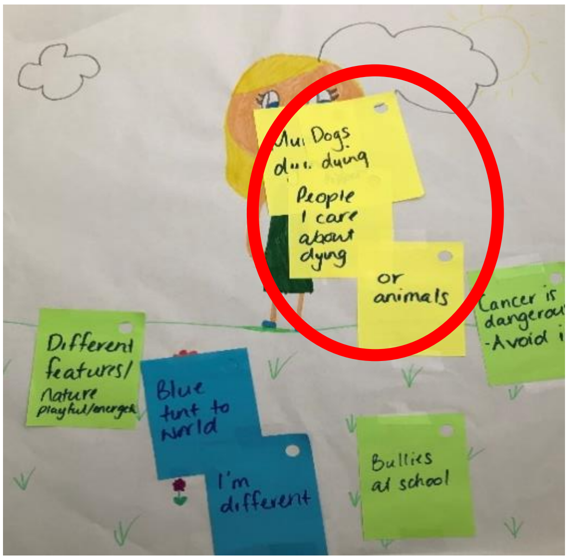

Figure 2. Child’s self-portrait and relative worries (Kayla; female: 10 years)

As evidenced in Figure 3, some children also worried about the likelihood of developing cancer. In this drawing, the proximity of the worry ‘getting cancer’ to the portrait, indicated that their own cancer risk was their most prevalent concern.

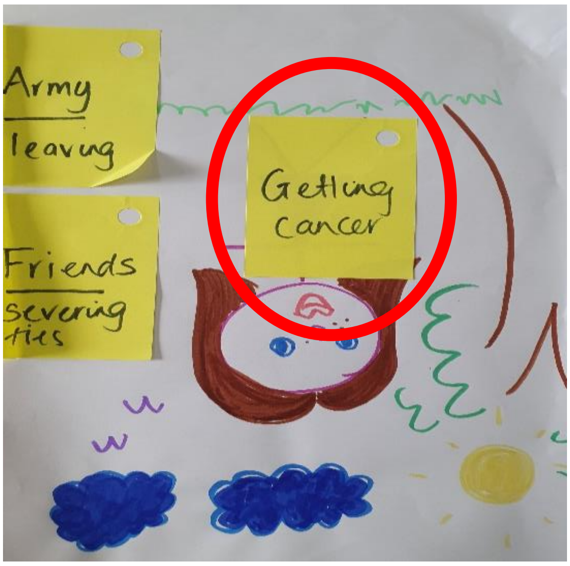

Figure 3. Child’s relative worries (Huxley; male*: 17 years)

**not a self-portrait, this participant preferred to use the researcher’s drawing.*

Often children's worries led to increased vigilance regarding their parent's health. This tended to impact negatively on them, particularly those whose parent was an outpatient, leading children to be increasingly exposed to the disease and treatment side-effects.

"I just want to go home every day... Because I want to stay with my mummy to make her feel better". (Arianna; female: 6.5 years).

Moreover, this worry persisted even when the patient was well or in remission.

Interviewer: "How did you deal with that worry?"

Child: "I don't think I really dealt with that worry. It sought of just lingered around". (Lucas; male: 12 years).

When this same child (Lucas) was asked about how this worry affected him, he stated, *"I don't think it had much of an effect on me then. I feel like it has more of an effect on me now because I know that my mum survived and what could have happened and what she did to keep it all [life] going".*

Comprehending their parent's cancer diagnosis.

Children's awareness of their parent's cancer diagnosis and their capacity to comprehend this and other related information, varied. However, most children indicated they knew very little about this.

"I don't know about it [cancer]... I just know that cancer is a bit dangerous… Because people that have cancer may die. ...I don't really know much about what sort of cancer she had or how she got saved. I just know that she had cancer and she was lucky enough to get saved" (Indigo; female: 8 years).

These children often referred to earlier experiences or knowledge to 'fill in the gaps', particularly if someone they knew had previously had cancer. However, this sometimes led to the formation of misconceptions about the disease.

Interviewer: "Can you tell me what you know about mum's cancer?".

Child: "Brain cancer, kills people" (notably, the parent did not have a brain cancer diagnosis).

Interviewer: "Did someone you know have brain cancer?".

Child: "It's granddad. He died". (Arianna; female: 6.5 years).

However, some children indicated they had no questions regarding their parent's diagnosis, and one child stated he preferred not to be further informed.

"No. I know that it's not life-threatening and that it's dying slowly. It's minimizing. So, that's all I want to know" (Darius; male: 13 years).

Talking about their parent's cancer diagnosis

Children's difficulties in comprehending their parent's cancer diagnosis appeared to also affect their capacity to talk about their parent's cancer diagnosis and articulate any thoughts, emotions, and questions they had about this. Many children (including older children) struggled to answer questions in more depth than 'yes or no' responses even when probed as per the interview schedule. Hence, they required ongoing discussion and support to drill down further and unpack what they knew about their parent's diagnosis.

Interviewer: "Do you know anything else about mum's cancer?".
Child: "No".
Interviewer: "Do you know if she's getting any medication for it?".
Child: "No".
Interviewer: "Are they giving her anything to make her feel better?".
Child: "Yeah. Medicine". (Arianna, female: 6.5 years).

One child indicated he regretted not asking more questions at the time, however, conceded that he had limited awareness of the diagnosis at the time and was unsure of what he needed to know, what he needed to ask, and how to ask.

Child: "When I look back it, I wished I'd asked more questions… I'd feel a sense of closure if I did ask…".
Interviewer: "Do you know what you would ask?".
Child: "I'm generally unsure of it, I just feel the need to know something".
Interviewer: "Is it something you can ask mum about?".
Child: "It might be, but I'm unsure of how to do this" (Lucas, male: 12 years).

All children required some level of facilitation by the interviewer to promote discussion. One child was particularly reluctant to speak. However, upon engaging in play and then moving to the children's activity (detailed in the methods section), he was encouraged to convey his understanding about his mother's diagnosis. This is evidenced in Figure 4, where he indicated the primary cancer site of his mother's cancer diagnosis.

Figure 4. Child's drawing of parent's cancer site (James; male: 6 years)

Being disconnected from their supports

Most children reported a loss of quality time spent with their ill parent.

Child: *"I spent more time with her before she got sick. She's having another operation to take the bag away and then we're going to have more time to be with her again".*

Interviewer: "Are you looking forward to that?".

Child: "I've been waiting for it for 1,000 years" (Arianna, female: 6.5 years).

And their parents' difficulties to take care of their basic needs such as preparing meals.

"When she got cancer, she couldn't do it [cooking] so she just gives us like baked beans or spaghetti." (Darius, male: 13 years).

Children also reported they had less opportunity to spend time with other support networks including extended family.

"Mummy can't drive that much so we can't really go down to (Location A) and (Location B) that much. So, I don't get to see my family because most of them live in (Location A)" (Batari, female: 8.5 years).

And many were unable to see friends during or outside of school.

"I miss my friends because most of them, they are not at home and we're not going to school" (Arianna, female: 6.5 years).

Most children were also required to give up sports and hobbies due to their parent's cancer diagnosis.

"Well, now I can't exactly go out on walks with the dog because Dad used to come with me and now, he can't drive me to dancing. I used to do dancing, tap, acro and I started jazz" (Sarah, female: 11 years).

Some children experienced greater upheaval and disruption to their lives, including integral relationships and support networks. For example, one family migrated to Australia for treatment, leaving their father, extended family, friends, school, and all other support networks.

Participant: "The one that made me happy really, really, really happy was my grandpa and my favourite auntie".

Interviewer: "In [home country]?".

Child: "Yep".

Interviewer: "So, you spent a lot of time with them, did you?".

Child: "Yep". (Indigo; female: 8 years).

Another family was required to relocate immediately following diagnosis from regional to metropolitan WA to receive treatment. Hence, there was a significant shift in the children's support networks available to them, with family and friends no longer close.

Interviewer: "When you found out that daddy was sick, and your family moved away, how did you feel then?".

Participant: "Worried... "That's when Mr. Worry Monster came. Until I made some friends". (Farrah; female: 7 years).

Needing someone to talk to

Children preferred to ask their parents any questions about the cancer diagnosis and, if parents were not available, then they would consider a teacher or other adults they perceived as knowledgeable (e.g., grandparent).

"I would ask my Mum, or I could ask my Dad. I would ask either one of them or maybe someone who was in the house. If I was with my grandma and granddad, I would ask them as well. I'm comfortable with asking anyone that is older than me, not my friends because they probably wouldn't know as much as I would." (Sarah; female: 11 years).

However, it appeared children did not have many options for talking to someone other than their parents. One child said he would be unlikely to chat to or ask questions of teachers or health professionals, indicating a perceived ‘gap’ between himself and these supports.

Child: “They all repeated the same thing, ‘if there’s anything you want to tell us, you can tell us…’. I genuinely don’t think that works…this doesn’t always fill the gap”.

Interviewer: “What’s the gap?”.

Child: “The gap is a feeling of emptiness, teachers saying you can get something off your chest is a feeling that it’s not enough, there’s a void between you and them that doesn’t make it feel like you can talk to them” (Lucas; male: 12 years).

As observed in Figure 5, this was further supported by the child’s drawing which indicated this gap identified between the child and health professionals, was something that concerned him.

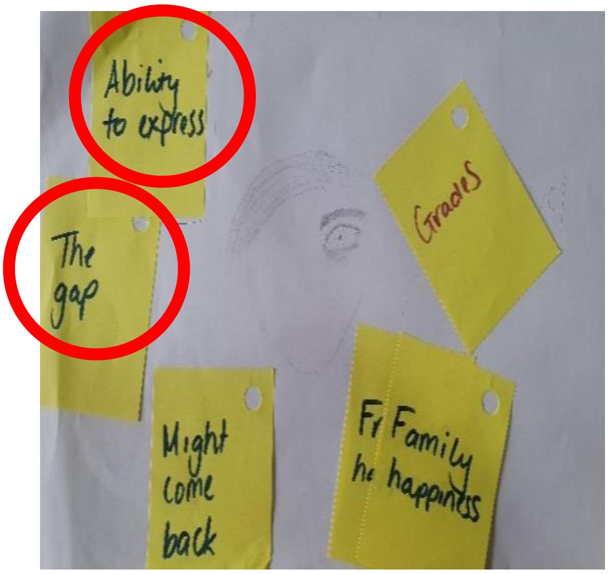

Figure 5. Child’s self-portrait and relative worries (Lucas; male: 12 years)

One child reported she would ask her play therapist any questions, however, when prompted, indicated she had little opportunity to ask questions during the sessions.

“The therapist only goes for 10 minutes – she asks questions. I don’t really get a chance to ask” (Batari; female: 8.5 years).

When asked if they would talk to their friends, most children indicated their friends were unlikely to understand or empathize with their situation, therefore they preferred not to.

"I would talk to my friends, but I can't ask them questions because I don't think they would understand them." (Sarah; female: 11 years).

Many children indicated they wanted to talk to someone about what they were going through. As observed in Figure 5, one child reported the need for an individual to help him process and 'express' complex issues such as managing extreme physiological sensations associated with anxiety and worry (e.g., racing heart) and cognitions around what would happen to his mother including radical changes due to the cancer diagnosis and treatment. Some children were also welcoming of meeting other children whose parent also had cancer.

"Sometimes yes, because they would be more likely to understand than some of my friends who have no family problems with that. Although they do try to help me, my actual friends, and they try to understand as much as possible, but sometimes you just can't understand" (Sarah; female: 11 years).

Discussion

This qualitative study investigated children's perspectives of their parent's cancer diagnosis and how it affected them. Our findings indicated when a parent was diagnosed with cancer, their children experienced heightened levels of ongoing worry and distress. This was influenced by childrens' difficulty with comprehending and talking about their parent's diagnosis and their complex thoughts and emotions associated with this. Yet, children appear to feel disconnected from their parents and other support networks who might provide this help and support. As such, children were in need of someone they felt they could talk to and who could help them understand what they were going through.

Children reported heightened levels of ongoing worry and distress associated with their parent's cancer diagnosis. They worried about parents' symptoms and disease outcome, treatment, recurrence, and death. While it is common for all children to experience thoughts around death and illness and be exposed to such concepts (Gaab et al., 2013), these thoughts were experienced as very intrusive for cancer patients' children. Patients' children bear witness to the physical and cognitive changes associated with the disease and treatment, which exacerbates their worries and distress; and there is a real possibility death may occur (Krauel et al., 2012). There was tendency for children's worries to generalize to family and friends, and for children to worry about their own likelihood of being diagnosed with cancer, which in some instances may be warranted based on the child's previous experiences with cancer and the possibility of hereditary (Werner-Lin et al., 2018). This appeared to be exacerbated for children whose parent was an outpatient and they were increasingly exposed to physical changes and had trouble escaping the impact. There is evidence for long-term consequences associated with even low levels of chronic stress in developing children, such as symptoms of Post-Traumatic Stress Disorder, anxiety and depression, obesity, and alcohol and substance abuse (see review by Wiss & Brewerton, 2020); which further supports suggestions that patients' children could remain vulnerable later in life (Bylund-Grenklo et al., 2016; Morris et al., 2018; Stoppelbein et al., 2006). Our findings support previous reports elucidating children's ongoing worry, distress, and threat to health-related quality of life, as imperative adverse challenges experienced by patients' children, requiring further research and clinical support (Hauken et al., 2018),

Children in this study demonstrated varying levels of knowledge and awareness regarding their parent's diagnosis, however, this was generally limited. Most children demonstrated difficulties comprehending their parent's diagnosis and disease related information associated with this; and struggled with articulating and unpacking their thoughts and emotions around this. In the absence of information, children were likely to construct their own meanings and answers, which often lead to misconstrued or inaccurate cognitions, and even magical thinking. Our findings are consistent with those reported in previous studies that have explored the impact of a parent's cancer diagnosis on children (Bugge et al., 2008; Christ et al., 1993; Zahlis, 2001). Open, timely, and age-appropriate communication with patients' children is imperative in the parental cancer literature; to mitigate children's levels of distress and resolve cognitive inaccuracies or perceptions of insufficient information provision, and to support children with adapting during their parent's diagnosis (Ellis et al., 2017; Krauel et al., 2012; Morris et al., 2018; Ohan et al., 2020). Yet, adults tend to focus on the more complex biological details of the diagnosis when speaking to children, and children find it difficult communicating their emotional problems to parents (Lewis et al., 2019). Parent's and children's appeal for guidance regarding communication continues to be well documented in the literature (see review by Walczak et al., 2018) however, remains an unresolved area of need among families.

While children in this study preferred to talk to and be supported by their parents; parents were often unavailable and they were limited regarding who they could seek out, including extended family and friends who were difficult to access or considered unlikely to understand. This is commonly reported in the literature (see review by Morris et al., 2018) however, concerningly parents are often overwhelmed by their own experiences and challenges associated with the cancer diagnosis, making their physical and mental availability to children challenging (Alexander et al., in review; Dencker et al., 2019). Furthermore, research evidences the parent-child relationship and family dynamics are integral to maintaining children's wellbeing, with parental psychological health being inextricably associated with children's (Krattenmacher et al., 2012; Niemelä et al., 2012). While some children in this study considered speaking to other children in similar circumstances, interventions of this nature (e.g., *Children's Lives Include Moments of Bravery (CLIMB)*, (Shallcross et al., 2016); *The On Belay Program*, (Tucker et al., 2013) are yet to prove effective at mitigating children's emotional and behaviour problems, particularly in the long term (Alexander et al., 2019; Ohan et al., 2020). Research that connects children with extended supports remains imperative and should continue to be an integral part of intervention research, however, future research should also continue to prioritize supporting the physical and mental capacity and accessibility of parents, to promote their availability to children (Alexander et al. in review).

Alternatively, health professionals who formed part of the parent's oncological team, were either not considered or were perceived as inaccessible by most children who were reluctant to approach them. Yet, there is suggestion in the literature that health professionals are well placed to identify or support cancer patients' children and provide a gateway entry into clinical systems (Alexander et al., 2020; Dencker et al., 2017). Health professionals are also reluctant to approach patients' children for reasons including a lack of knowledge or confidence in doing so, as the primary focus of their care is the patient, and their expertise is adult based (Alexander et al., 2020; Dencker et al., 2017). Moreover, children are generally protected and kept from clinical settings by the patient (Alexander et al., in review; Dencker et al., 2019), hence, exacerbating patients' children's invisibility to health professionals and clinical systems. This appears to be a systemic gap whereby intervention, such as a family support worker or furthering health professionals' education, could promote health professionals and children’s capacity to seek out one another, thus alleviating this burden on overwhelmed parents.

In this study all children required some level of support or resources to assist them with talking about their parent’s cancer diagnosis. Expressing their thoughts and feelings appeared to be challenging, and most children were avoidant or deflective of this. Even older children reported their difficulties with expressing their worries. The inclusion of play and arts-based activities helped children in this study construct and express their thoughts and emotions. For some reluctant children, these approaches facilitated discussion; for others, it helped them comprehend and articulate their thoughts. This approach also enabled the researcher to drill down further regarding children’s meaning behind their verbal responses. This aligns with current literature evidencing fundamental differences in communication techniques, and comprehension levels, between children and adults, yet there is a continued expectation for children to communicate at an adult level (Landreth, 2002; O'Reilly & Dolan, 2016). Literature on communicating with children advocates for such innovative approaches as those used in this study (Landreth, 2002; O'Reilly & Dolan, 2016). Increasing recognition for including children in research also highlights the need to develop tools, resources, and guidelines that promote effective communication with children (Australian Research Alliance for Children and Youth & New South Wales Commission for Children and Young People (2009). 2009).

Limitations

It is important these reported findings are interpreted with the limitations of this study in mind. The age range of participants was broad; focusing on a narrower age range may have yielded different findings, and this could be considered in future studies. Participants were recruited through opt in methods and predominantly through cancer support services and Comprehensive Cancer Centres. Therefore, it is likely the participants in this sample came from families/parents with a greater psychological awareness and health literacy. This is commonly reported in similar studies (Beale et al., 2004; Bell & Ristovski-Slijepcevic, 2011; Bugge et al., 2009; Park et al., 2016), however a sample from a more diverse background respectively, may be necessary. The interview techniques used were novel and developmentally appropriate; replication of this approach appears warranted to enhance authenticity.

Clinical significance

The findings of this study can be used to inform current approaches to communicating and consulting with children living with parental cancer. Children are also disconnected from other supports outside of their parents, which is concerning as parents are often not positioned to attend to their children's needs due to the challenges associated with the disease and treatment. Hence, our findings can also be used to inform guidelines and practice in psycho-oncology and intervention research by promoting the need for parents to be adequately supported, and for children to be appropriately connected with supports and resources outside of their family where necessary.

Conclusion

Children living with parental cancer are at heightened risk for psychosocial, emotional, and behavioural problems. Despite increasing research interest regarding how these children are affected, there is little consultation with children themselves. This is concerning considering the documented inaccuracies between child self and parent proxy-reports. Interviews with patients' children revealed children experience heightened levels of ongoing worry and distress when a parent is diagnosed with cancer and feel a level of disconnection from usual support systems, including parents and friends, during this critical time. Comprehension and communication barriers identified in this study can be used to inform future intervention research and clinical practice to enable children and adults to effectively communicate with each other.

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CHAPTER 7 A model conceptualising how children are affected by parental cancer: A constructivist grounded theory approach[7]

Chapter Overview

This chapter presents a detailed discussion of this thesis, including the study implications, limitations, and conclusions. How cancer patients' children are affected by their parent's diagnosis is considered from the perspectives of children, parents/patients, and health professionals. The overarching theme, children are '*not seen and not heard',* and the mechanisms which contribute to this outcome are discussed through the lens of the theoretical framework underpinning this study. An explanative model, the Alexander's Children's Cancer Communication (ACCC) model for children with a parent with cancer, is proposed. This model addresses current limitations identified by the systematic review presented in chapter 2, through providing a conceptual explanation of how children are affected by their parent's cancer diagnosis. The ACCC model can be used to improve the methodological rigor of future intervention studies for cancer patients' children. A series of clinical recommendations are also provided which can promote the timely support of cancer patients' children. This chapter ends with the conclusions of this thesis.

What this research adds to the literature:

- There are communication and interaction barriers among children, parents, and health professionals that render children to be '*not seen and not heard'*

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[7] This chapter has been prepared for submission to the journal, Frontiers in Psychology (Psycho-Oncology).

by adults. Consequently, children are left unsupported when a parent is diagnosed with cancer.

- Children are worried and distressed by their parents' cancer diagnosis because they are alone in dealing with the diagnosis.
- Parents are overwhelmed by the practical challenges of the cancer diagnosis, which makes it difficult for them to tend to their children's needs.
- Health professionals are not detecting patients' children due to clinical and systemic barriers which reduce children's visibility to health professionals.

Clinical recommendations from this research include:

- Improving health professionals' developmental knowledge of children.
- Provision of a communication tool to assist health professionals' communication with children.
- Routine and standardised screening processes for detecting patients' children and referring them on to the appropriate supports and resources.
- Practically supporting parents with the challenges associated with parenting young dependent children and having a cancer diagnosis.

A conceptual model depicting how children are affected by parental cancer: A constructivist grounded theory approach

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Declarations

Consent to participate: Informed consent was obtained from all individual participants included in the study

Consent for publication: The authors affirm that human research participants provided informed consent for publication of their data

Availability of data and material: Data is available upon request

Code availability: Not applicable

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Abstract

Cancer patients' children are vulnerable to psychosocial and behavioural issues. The mechanisms underlying how children are affected by their parents' diagnosis are unknown, which warrants further research. This study investigated how children are affected by their parents' cancer diagnosis and provides a theoretical model conceptualising this experience. Informed by methods of grounded theory, embedded within a social constructivist framework, 38 informants (15 health professionals; 11 parents; 12 children (5 to 17 years) were interviewed using a semi-structured format. Three themes were identified: (i) children were worried and distressed because they felt alone, (ii) parents were unable to tend to children's needs because they were overwhelmed by practical factors, and (iii) HPs were not detecting children due to barriers that affected their visibility in clinical settings. The proposed Alexander's Children's Cancer Communication (ACCC) model and clinical recommendations made can be used to guide clinical practice and development of future intervention research.

Introduction

Globally, the number of dependent children living with a parent with a cancer diagnosis remains unreported. However, estimates in the United States indicate that in 2010 there were approximately 2.85 million children aged 18 years and under whose parent had been diagnosed with cancer (Weaver et al., 2010). In Australia, there are currently no population data regarding the prevalence and characteristics of children living with parental cancer, though a recent longitudinal study conducted in Western Australia (WA) reported that between 1982 and 2015, 25,901 children (approximately 24% of those between 0-11 years) experienced a parent's diagnosis of cancer (Martini et al., 2019). The five-year survival rates among Australian cancer patients aged 25 to 49 years are rising (Australian Institute of Healtha nd Welfare [AIHW], 2019), meaning that patients and their families, including patients' children, are living longer with the impact of a cancer diagnosis (Werner-Lin & Biank, 2009). Consequently, many of these patients will be supporting dependent children while also coping with their diagnosis (Shah et al., 2017; Syse et al., 2012; Weaver et al., 2012), presenting a major challenge for this cohort.

Research indicates the overall adjustment and emotional wellbeing of patients' children is negatively affected, rendering children at risk of developing various maladaptive psychosocial, emotional, and behavioural stress responses (Morris et al., 2018; Walczak et al., 2018). These include somatic complaints (Hauskov Graungaard et al., 2019), separation anxiety, high levels of distress, confusion, rumination, worry and intrusive thoughts (Ellis et al., 2017; Ghofrani et al., 2019; Osborn, 2007). While these negative symptoms may dissipate over time for some children, many children are likely to remain vulnerable to long-term problems, including self-injury and post-traumatic stress symptoms (Bylund-Grenklo et al., 2016; Lundberg et al., 2020; Stoppelbein et al., 2006). Despite these negative effects, there are also reports of resilience building and the potential for post-traumatic growth among cancer patients' children (Osborn, 2007; Phillips & Lewis, 2015; Walczak et al., 2018). Age, gender, cancer stage, pre-existing comorbidities, parent's marital status and psychological health are factors which appear to influence how children are affected (Huizinga et al., 2010; Jeppesen et al., 2016; Morris et al., 2018; Visser et al., 2007; Walczak et al., 2018). However, it remains uncertain what underlying mechanisms may affect children's capacity to cope and adjust to their parent's cancer diagnosis.

Parents have indicated they are uncertain how to support children and seek clinical or therapeutic help (Dencker et al., 2019), and it has been identified that children are undetected in clinical and health systems and typically not on the radar of the patient’s oncological treating team (Arber & Odelius, 2018; Niemelä et al., 2012). Compounding these issues, parents are unlikely to address concerns about their children with HPs and HPs often do not discuss the subject of children with patients (Dencker et al., 2019). Yet, children prefer to be supported by parents, and HPs are well placed for detecting distress and referring children to appropriate services (Dencker et al., 2019). Consequently, children do not appear to be receiving the help they need and are often left to support themselves (Alvariza et al., 2017; Helseth & Ulfsaet, 2003). Much of the literature focuses on supporting patients and their spouses, with little consideration of the needs of patients’ children (Grabiak et al., 2007; Huizinga et al., 2011).

There is limited reporting of interventions for patients’ children in the empirical literature (Alexander et al., 2019; Ellis et al., 2017; Walczak et al., 2018). Participants’ qualitative feedback reported in intervention studies supports their feasibility and acceptability, indicating there is a need for interventions among parents and children (Alexander et al., 2019). However, recent systematic reviews indicate interventions are not effective in mitigating children’s various psychosocial and behavioural outcomes, including depression and anxiety (Alexander et al., 2019), and there is demand for more empirically developed and rigorously evaluated interventions (Ellis et al., 2017; Ohan et al., 2020; Walczak et al., 2018). Interventions also lack a theoretical framework or model that conceptualises the mechanisms which may explain how children are affected by their parent’s diagnosis (Alexander et al., 2019; Ohan et al., 2020). A new robust theoretical model must therefore be developed, and subsequently used to inform, any future intervention studies designed to improve psychosocial and behavioural outcomes among children experiencing their parent’s cancer diagnosis.

Aim

This study explored how children are affected by their parents’ cancer diagnosis, from the perspectives of children, parents, and health professionals, to inform the development of a new theoretical model.

Methods

An integrated theoretical approach combining symbolic interactionism (Blumer, 1969) and Ecological Systems Theory (see Figure 1) (Bronfenbrenner, 1996) was used to provide the theoretical lens for developing an explanatory model conceptualising how children are affected by their parent's cancer diagnosis. This approach has been used in other studies investigating children's social experiences (e.g., Migliaccio & Raskauskas, 2015; Thornberg, 2018) and was deemed appropriate for the purposes of this study as it accounts for the high level of influence children's social interactions and the environment has on their developmental outcomes when a parent is diagnosed with cancer.

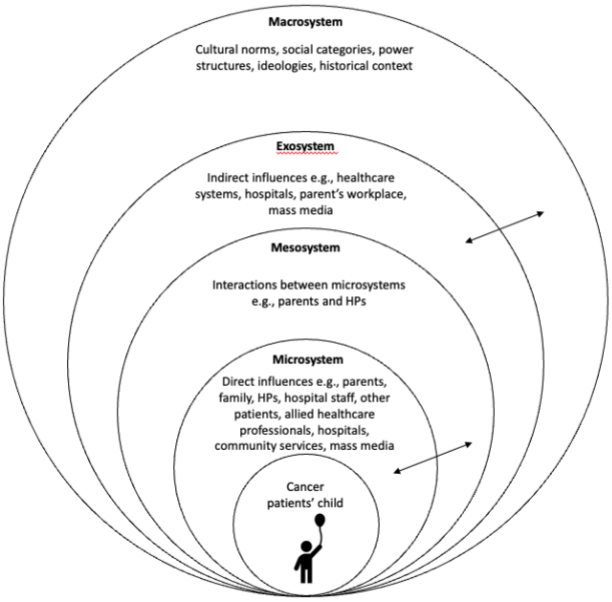

Figure 1. Adaptation of Bronfenbrenner's (1989) Ecological Systems Theory model depicting an example of the systems and subsystems that influence how children are affected when a parent is diagnosed with cancer.

Constructivist grounded theory informed the methodology and methods used in this study (Charmaz, 2006; Charmaz, 2014). This methodology aims to develop a detailed understanding of a person's unique social experiences (Charmaz, 2006; Charmaz, 2014). It adopts flexible research methods and recognises the person's construction of reality is a co-constructive process that occurs between the participant and the researcher. Such adaptive methods are important among diverse populations, particularly children (Bennett, 2016; Zandt, 2017). Also, rather than a simple description of events, this methodological approach enabled us to produce a theoretical conceptualisation of how children are affected by their parent's cancer diagnosis (Charmaz, 2006; Charmaz, 2014).

Ethics approval

Hospital and University ethics approvals were received for this study.

Participant recruitment

Three key informant groups were recruited for this study: HPs, parents, and children. HPs were initially recruited through a Comprehensive Cancer Centre at a metropolitan tertiary teaching hospital in Perth, Western Australia. HPs within the Centre were approached via one of the researchers (MOC) contacts and asked to advise potential participants of the study. Fliers were also posted on bulletin boards within the hospital and centre. Please see Table 1 for participant inclusion criteria. Potential participants either contacted the primary researcher directly or were contacted by the researcher via email. A mutually convenient time and location was then arranged. Participation was voluntary. Participants were provided with an information sheet and signed a consent form prior to the interview. Children of recruited parents were also given the option to be interviewed and their interviews were conducted independently of their parents. Data analysis and recruitment occurred concurrently. As new themes emerged, theoretical sampling was used to explore these further by approaching participants considered to have insight regarding novel themes (Charmaz, 2006; Charmaz, 2014; Glaser et al., 1968). Recruitment, interviews, and analysis continued until the data was considered rich and detailed, and no new categories were emerging therefore indicating data saturation (Charmaz, 2014; Corbin & Strauss, 2008).

Table 1.

Participant Inclusion Criteria

Population	Inclusion criteria
HPs	• Must be experienced in providing health care to patients with cancer who have a child or adolescent (up to the age of 18 years) living at home.

Parents	• Must be a parent diagnosed with cancer or a parent whose partner has been diagnosed with cancer, at any stage of the cancer diagnosis. • Must have a child living with them aged 18 years or below.
Children	• Must be living at home with a parent who has been diagnosed with cancer. • Must be 18 years and under.

Participants

A total of 48 participants were interviewed between April 2017 to June 2018. This included 15 HPs, 11 patients and spouses of patients, and 12 children. HPs were predominantly female (80%) with a mean age of 51.46 (±10.5) years. Parents were also mostly female (90%) with a mean age was 39.7 (±7.44) years. Forty-five percent of parents were spouses of a parent with a cancer diagnosis. Just over half of children participants were female (58%) with a mean age of 9.2 (± 3.5) years. See Table 2 for a summary of participants' demographics.

Table 2.

Participant demographics

Health Professionals	Number of participants	n = 15
Age	Range	31 – 71 years
	Mean age (SD)	51.21(±10.14) years
Gender	Female	80%
	Male	20%
Role	Cancer Nurse Coordinator	n = 3
	Psychosocial support worker or other allied health worker	n = 6
	Nurse practitioner	n = 1
	Clinical/oncological specialist	n = 3
	Clinical psychologist/psychiatrist	n = 2
Years of relevant experience	≤10 years	n = 5
	≤20 years	n = 4
	≤30 years	n = 4
	>30 years	n = 2
Interview method	Face to face	n = 8
	Telephone	n = 7

Parents	Number of participants	n = 11
Age	Range	28 – 52 years
	Mean age (SD)	39.7 (±7.44) years
Gender	Female	91%* or *n* = 10
	Male	9%* or *n* = 1
Health status	Patient	5
	Partner	6
Marital status	Married	9
	Separated / Divorced	1
	Widowed	1
Number of children**	1 child	4
	2 children	4
	3 children	2
Age range of children**		1 to 15 years
Cancer type (primary)**	Bowel cancer	2
	Brain	1
	Breast	1
	Burkitts lymphoma	1
	Lymphoma	1
	Melanoma	1
	Non-Hodgkin's Lymphoma B cell	1
	Lung	1
	Oral	1
Cancer stage** (at time of interview)	II	3
	III	1
	IV	3
	Not reported / remission / deceased	3
Ethnicity	Australian	82% or *n* = 9
	Indonesian	9% or *n* = 1
	Malaysian	9% or *n* = 1
Education	Postgraduate	4
	Tertiary	5
	Other	2

Children	Number of participants	n = 12
Age	Range	5 – 17 years
	Mean age (SD)	9.46 (±3.43) years
Gender	Female	58% or *n* = 7
	Male	42% or *n* = 5

Cultural background	Australian	75% or *n* = 9
	Indonesian	17% or *n* = 2
	Malaysian	8% or *n* = 1
Parent with cancer	Mother	50% or *n* = 6*
	Father	50% or *n* = 6*
Parent’s primary cancer diagnosis**	Bowel cancer	2
	Brain	1
	Breast	1
	Burkitt’s lymphoma	1
	Lymphoma	1
	Melanoma	1
	Non-Hodgkin's Lymphoma B cell	1
	Lung	1
	Oral	1
Parent’s cancer stage**(at time of interview)	II	3
	III	1
	IV	3
	Not reported / remission / deceased	3

* *n* = 3 sets of siblings (total = 7), therefore their parent with cancer was counted multiple times

** total number of patients included in the study was *n* = 10 (see Alexander et al., in review)

Interviews

All interviews were conducted by the primary researcher (EA, female, PhD candidate and experienced interviewer). Interviews were semi-structured, which enabled topic consistency while also promoting alternative lines of enquiry, further explanation, and examples of topics where relevant. This also encouraged participants to provide their own unrestricted perspectives. The focus of interview questions was to explore how participants perceived patients’ children were affected by their parent’s cancer diagnosis. The interview schedules were guided by the research question, a general literature review, and findings from a systematic review (Alexander et al., 2019). Interview schedules are documented in the relevant publications (HPs, see Alexander et al., 2020; parents, see Alexander et al., in review a; and children, see Alexander et al., in review b) or see supplementary data 1. Interview durations were as follow: HPs: 43 minutes (M = 42.69 (±22) range: 14.32 – 82.52); parents: 46 minutes (M = 45.88 (±10), range: 27.36 – 73.14); and children: 38 minutes (M = 37.13 (±22), range: 17.57 – 71.44).

Children's activity

A novel approach was developed and used during the children's interviews to facilitate their capacity to articulate their responses to interview questions. This was influenced by drawing and arts-based approaches or techniques (Akesson et al., 2014; Cohen-Liebman, 1999) which are used in participatory research among children vulnerable child populations such as those affected by sexual abuse (Katz & Hershkowitz, 2010; Veltman & Browne, 2002) and war (Green & Denov, 2019; Miles, 2000) often due to their ability to promote recall (Veltman & Browne, 2002). For more details regarding this approach, please refer to Alexander et al. (in review b).

Data collection

Individual HP interviews took place in person in the participant's workplace (*n* = 8) or via a scheduled telephone call (n = 7). Individual parent interviews were conducted in the participants' homes (*n* = 4), at Curtin University (*n* = 3), temporary accommodation (*n* = 2), place of work (*n* = 1), or the tertiary hospital (*n* = 1). Children's interviews were conducted in the same location as their parents; however, parents were not in the room. Informed consent was received from all participants. Children were provided developmentally appropriate information sheets and verbal assent was attained as per the National Statement on Ethical Conduct in Human Research chapter 4.2 (National Health Medical Research Council ([NHMRC], 2018). Observational notes and journaling were used to record notable details regarding context and behaviours. Pseudonyms were used for all children's names to ensure confidentiality and anonymity. For more details regarding the data collection processes please refer to the relevant publications (HPs, see Alexander et al., 2019); parents, see Alexander et al. (in review a); and children, see Alexander et al. (in review b).

Data analysis

Interviews were digitally recorded and transcribed verbatim. Using methods of constructivist grounded theory, transcribed data were analysed using initial line-by-line coding of the first five transcripts focusing on gerunds (actions and processes) to identify codes. Data and codes were then transferred to Microsoft excel to index the data into manageable chunks and develop preliminary themes. Transcripts were iteratively reviewed by members of the research team, and themes were discussed and refined. Data and themes were then transferred to NVivo12 where the remaining transcripts were coded, while remaining open to identifying further themes. Methods of constant comparison were used to elevate themes and develop higher order categories (Charmaz, 2006; Charmaz, 2014). Memoing techniques were also used to support themes to be moved from the descriptive to the analytical level (Charmaz, 2014; Glaser et al., 1968). For more details regarding the data analysis process please refer to the relevant publications (HPs, see Alexander et al., 2020; parents, see Alexander et al. (in review a); and children, see Alexander et al. (in review b). Reference to guidelines and criteria outlined by Pope and Mays (2006) and Braun and Clarke (2006) promoted analysis rigor. The Consolidated Criteria for Reporting Qualitative research guidelines ([COREQ] Tong et al., 2007) were also used to promote study quality and reporting rigor.

Findings

In this study, the perspectives of children, parents, and HPs were explored to understand how children are affected by a parent's cancer diagnosis. Three major themes were identified: i) children were worried and distressed because they felt alone, ii) parents could not tend to children's needs because they were overwhelmed by the practical factors of a cancer diagnosis, and iii) HPs were not detecting children's distress because there were barriers which affected children's visibility. Central to these three themes was the overarching concept that when a parent was diagnosed with cancer, their children were *not seen and not heard*. These themes are elaborated on and details of a proposed model that explicates these findings are presented below (Charmaz, 2014).

Children

Worried, distressed, and alone.

Following a parent's cancer diagnosis, their children experienced heightened levels of ongoing worry and distress. While this worry and distress varied for children based on factors such as their age and personality traits, for all children this was greatly influenced by circumstances such as the patient's (parent's) health status, hospitalisation, and changes to treatment plans

Interviewer: "You feel worried and frustrated a lot of time?"

Child: "Yes".

Interviewer: "When do you feel happy?"

Child: "When Mummy's okay and she's doing stuff" (Batari; female: 8.5 years).

This worry and distress was very intrusive for children, and consequently children were often hypervigilant about their parent's health and any changes, *"I just want to go home every day... Because I want to stay with my Mummy to make her feel better"* (Arianna; female: 6.5 years). Children whose parent was an outpatient appeared more vulnerable as they were constantly exposed to, and unable to escape from, the disease and treatment side-effects

"Her [patient] feet look bad. When she walks, her feet hurt. That's why she always has her slippers on. But then they make a weird noise at the night. I can't sleep and [sister] can't sleep" (Arianna; female: 6.5 years). Even after the parent was in remission their children continued to experience ongoing levels of heightened worry and distress, *"I don't think it (worry) had much of an effect on me then. I feel like it has more of an effect on me now because I know that my Mum survived and what could have happened and what she did to keep it all [life] going"* (Lucas; male: 12 years). This persistent worry and distress was similarly observed in children who were bereaved *"I worry about the dogs dying. I worry about Mum dying. I worry about all of my family, really"* (Kayla; female: 10.5 years, her parent had died). This participant also evidenced these worries and concerns as their most prevalent worries in their drawing (see Figure 2).

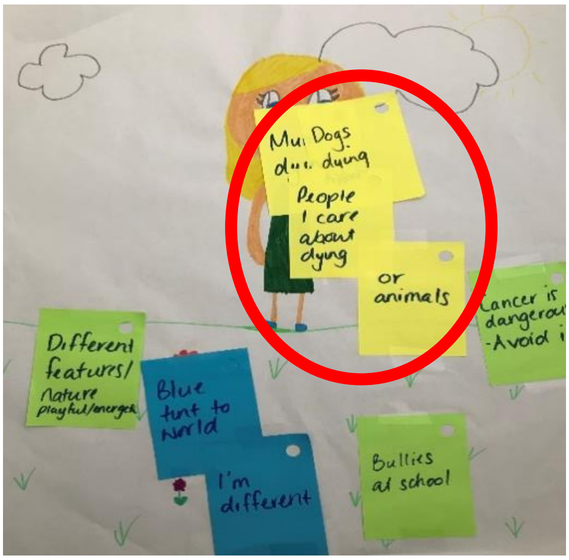

Figure 2: Child’s self-portrait and relative worries (Kayla; female: 10.5 years)

However, children did not appear to have much support to help them cope with this worry and distress. Most preferred to be supported by parents, however, felt a loss of quality time with parents.

Child: “I spent more time with her before she got sick. She’s having another operation to take the bag away and then we’re going to have more time to be with her again”.

Interviewer: “Are you looking forward to that?”

Child: “I’ve been waiting for it for 1,000 years” (Arianna, female: 6.5 years).

They were also conscious of not burdening their parents who they recognised were already struggling with the emotional, physical, and practical aspects of the cancer diagnosis *“When she got cancer, she couldn’t do it [cooking] so she just gives us like baked beans or spaghetti”* (Darius, male: 13 years). They also felt alone and disconnected from other supports they would normally have, such as their extended family, friends, and school and sports communities, *“I miss my friends because most of them are not at home and we’re not going to school”* (Arianna, female: 6.5 years). Most children had questions about their parent’s cancer diagnosis, however, while children preferred to speak to their parents about these *“I would ask my Mum, or I could ask my Dad. I would ask either one of them or maybe someone who was in the house”* (Sarah; female: 11 years). Their limited understanding and lack of sufficient knowledge about their parent's cancer diagnosis was evident, which suggested this might not be occurring.

Interviewer: "Can you tell me what you know about mum's cancer?"

Child: "Brain cancer, kills people" (notably, the parent did not have a brain cancer diagnosis).

Interviewer: "Did someone you know have brain cancer?"

Child: "It's Granddad. He died" (Arianna; female: 6.5 years).

Many children felt they needed to talk to someone, however, considered their friends were unlikely to understand and they found it difficult to talk to adults, including their parents. Most children found it challenging to comprehend their complex thoughts and emotions and articulate these to adults, indicating their need for help with this.

Interviewer: "Do you know what you would ask?"

Child: "I'm generally unsure of it, I just feel the need to know something".

Interviewer: "Is it something you can ask Mum about?"

Child: "It might be, but I'm unsure of how to do this" (Lucas, male: 12 years).

One child indicated they needed help to express their thoughts and feelings and that this was a great concern for them (see Figure 3).

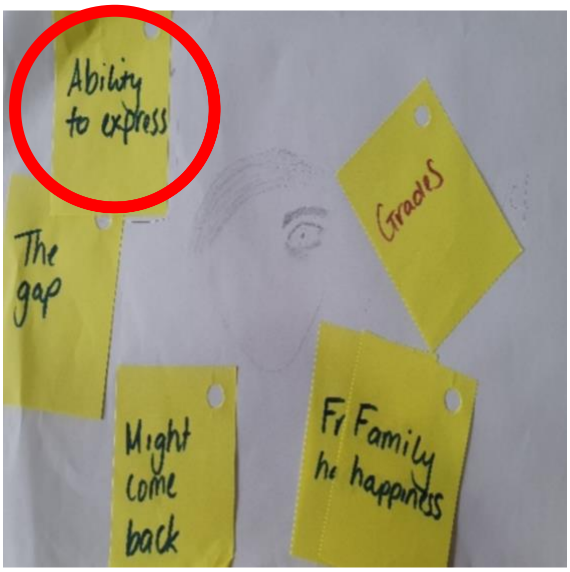

Figure 3: Child's self-portrait and relative worries (Lucas; male: 12 years)

Another child who was reluctant to speak to the interviewer and whose parent assumed they had little awareness for their diagnosis, was encouraged to demonstrate their knowledge of their parent's diagnosis through drawing, whereby they correctly indicated the primary cancer site of the diagnosis (see Figure 4).

Figure 4: Child's drawing of parent's cancer site (James; male: 6 years)

Children were also unlikely to approach HPs for support, as they did not consider them in the first place and assumed HPs would not be able to help them, which was supported by the experiences of some children who found their engagement with HPs ineffective, *"The* [child's] *therapist only goes for 10 minutes – she asks questions. I don't really get a chance to ask*" (Batari; female: 8.5 years).

Parents

Children's needs are unattended

Parents were typically overwhelmed and burdened upon receiving the diagnosis which rendered them unable to tend to children's needs. They were often dealing with their own shock and disbelief elicited by the cancer diagnosis, while endeavouring to comprehend vast amounts of complex technical information which they felt could be more effectively and supportively disseminated by HPs, *"The information comes so fast and quick; you're making 'informed decisions'… how can you make 'informed decisions' when information comes in that thick and fast and in* *things that we know nothing about"* (Parent 2). Consequently, while parents did their best to talk to children and answer any questions about the diagnosis, they were simultaneously trying to understand the information provided and work out what was happening *"We weren't completely sure ourselves. So, we didn't really want to tell the children [about the diagnosis]"* (Parent 4). As such, parents found it difficult to know how much to tell children *"It's probably more just trying to protect them… it's hard to know how far you go and what you need to tell them"* (Parent 5).

Parents were also overwhelmed and burdened by the practical factors of a cancer diagnosis, including navigating complex healthcare systems

"If you have to phone to change an appointment, you don't go to a receptionist. You go to some third party who may or may not be able to change an appointment or answer a question, so it's absolutely hopeless whatever that system is, so we don't even bother" (Parent 1)

and implementing life changing decisions to accommodate diagnosis and treatment,

"We're sitting there and we're having to decide on the spot whether or not he's going to have further treatment" (Parent 7).

Often the healthy parent was required to take on the ill parent's role and responsibilities *"She's [wife] taken a lot of the load of stuff that I would have dealt with before. She deals with most of the financial stuff now; just trying to not get me stressed out so I can concentrate on getting better"* (Parent 4) and felt forced between being a parent to their children or being the patient's advocate *"To manage the illness – I felt I was put in the position of having to choose between parenting and supporting (patient) through to the end of his life"* (Parent 10). Alternatively, the ill parent felt divided between prioritising their health and the impact of the disease and the demands of treatment, with their responsibilities of being a good parent and partner *"I still don't think they [children] understand how tired and sick I am. Sometimes it gets overwhelming. They get quite demanding… so trying to explain to them but trying not to make them feel like I'm getting cross at them"* (Parent 1).

Parents found themselves challenged in maintaining a level of stability and normalcy for their children.

"There's always something that comes up. We've tried to plan for the best but expect the worst"

Often children's activities, including sports, hobbies, social activities, and visiting friends and extended family were curtailed or stopped due to the demands and constraints of the diagnosis and treatment *"We had them enrolled in gymnastics and basketball… everything was just a bit full on when I got sick… we decided to strip back all the things we were doing with the kids"* (Parent 3).

Significant upheaval was also unavoidable at times with some families needing to relocate to be closer to treatment options and change schools *"I rang the Leukaemia Foundation; started packing the house. I changed the kids' school; I got all that done within that week because the next week we had to be in Perth"* (Parent 5). This was particularly challenging for rural and regional families where relocation was not optional. Families where the patient was an out-patient faced unique challenges such as isolating and implementing extreme routines around hygiene and treatment particularly when the patient was neutropenic.

"While he's neutropenic you can eat an apple, but you've got to wash your hands; wash your face before you kiss or hug dad; you've just got to be really conscious. Lots of extra handwashing. We have good hygiene, but I'm just seeing bugs everywhere. It's cleaning constantly" (Parent 2).

Despite parents wanting to protect their children from being exposed to the physical, psychological, and mental detriments of cancer, this was often impossible, particularly when the patient was an out-patient,

"The children pick up on my stress. They certainly pick up on his stress. My five-year-old was wetting the bed and the more [patient] got sleep deprived because he was getting up in the middle of the night changing sheets, the less tolerant of it he became and that becomes like a negative cycle" (Parent 9).

the family had limited childcare support,

"The first time I brought her to the hospital, she saw a lot of patients in very bad conditions" (Parent 8).

or there was an emergency.

"He [patient] got very sick and ended up in the high intensity unit because they had to call a code blue, which was probably a bit of a shock seeing Dad so sick in hospital, and for [child] – that was probably the hardest week for him. It was stressful for all of us; me trying to still work, going into hospital every night" (Parent 4).

Health Professionals

Children are invisible

There were many barriers that rendered children invisible among HPs meant children were not being detected and referred on to the appropriate staff or services that could assist with this. For instance, there were no routine and standardised screening processes in place to detect systematically patients' children and refer them on, therefore relying on HPs to remember and implement these processes themselves. However, this was not routinely occurring, and HPs typically relied on parent's telling them they had children, rather than asking them about children.

"That's [screening] something we initiate ourselves. We normally try to get as much information about their social life and their family life as we can and then if they tell us they do have kids, then we explore" (HP5).

Moreover, there was confusion around who was responsible for screening for patients' children and subsequently children were typically overlooked as it was assumed someone else was doing this, *"If everyone is thinking the social worker will make a referral, it's leaving it to the social worker, but they don't automatically see every patient. So, there's a lot that can be overlooked"* (HP11).

When considering approaching children, HPs were aware that conversations with children needed to be child centric, that is, conversations needed to be timely and ongoing to accommodate children's processing of information and developing cognitive sophistication.

"*Sometimes they [children] will process it through play therapy, but not be able to articulate it verbally how they're feeling. Then, once the diagnosis has got to a safer distance, they might be able to engage in some verbal dialogue, or as they're getting a little bit older, they might be in a position to articulate and want to revisit what's happened"* (HP9).

However, most HPs felt they did not possess sufficient developmental knowledge or training to facilitate this level of communication with children. Consequently, HPs were reluctant to approach children as they felt they could potentially do more harm than good by opening a conversation they were not equipped to have.

"I'm not experienced in child psychology. I really am fearful that I would be doing an injustice opening up a conversation that I didn't have the tools to complete" (HP3).

Community services that were experienced with cancer patients' children, and had resources and programs available to support them, were reliant on clinically based HPs to identify children, recall their services, and then refer or direct children to these services, *"We are relying on nurses and people in the healthcare profession to remember about [service]. It is not usually part of their standardised screening, but ultimately it would be good for it to be so that more referrals can come to [service]"* (HP11).

Yet, clinical HPs indicated their ongoing need for support with this; to promote their recall and awareness of these services in the first instance, and to inform them of their current operational status, the services they provided, and their intake criteria. These HPs felt that it could be more detrimental to send children to a service that was no longer operational or not designed to support their needs, *"Probably there are a number of supports out there, but it's having access to them and working out who can have access to those different things"* ... *"More education and knowing the usual things of being able to signpost people to where help can be sought"* (HP7).

Parents preferred to shield their children from hospital and clinical settings, which exacerbated children's lack of visibility among HPs through limiting HPs' and children's capacity to seek out one another.

"I feel a lot of the time they shield the kids, so they don't bring them in" (HP4).

HPs also recognised that children were reluctant to talk to HPs, including those who were experienced with children and positioned to support them,

"With the ones that are reluctant to talk, it is a lot more challenging, and I feel that even when I am trying to build more of a rapport with them and sneakily get some questions in here and there, it's not always going to go well" (HP12).

Furthermore, children typically wanted to protect their parents by concealing their thoughts and feelings from parents and HPs. Thus, made it difficult to recognise when children were struggling, *"Sometimes there are ones that have never really spoken about it because they're afraid of upsetting their parent or whatever the circumstance might be"* (HP12).

Explanatory model: How children are affected by a parent's cancer diagnosis

Based on the perspectives of children, parents, and HPs, the overarching concept that cancer patients' children were *not seen and not heard,* emerged. When a parent was diagnosed with cancer, patients' children were unlikely to receive the timely support needed to help them cope with their heightened levels of worry and distress, resultant from the diagnosis. This appeared to be due to the compromised nature of children's interactions with parents and HPs. The mechanisms which underpinned the nature of these interactions were i) a breakdown of communication among children, parents, and HPs, and ii) barriers that prevented children, parents, and HPs from interacting with each other. These mechanisms are visually conceptualised in the proposed explanatory model titled Alexander's Children's Cancer Communication (ACCC) model (Figure 5).

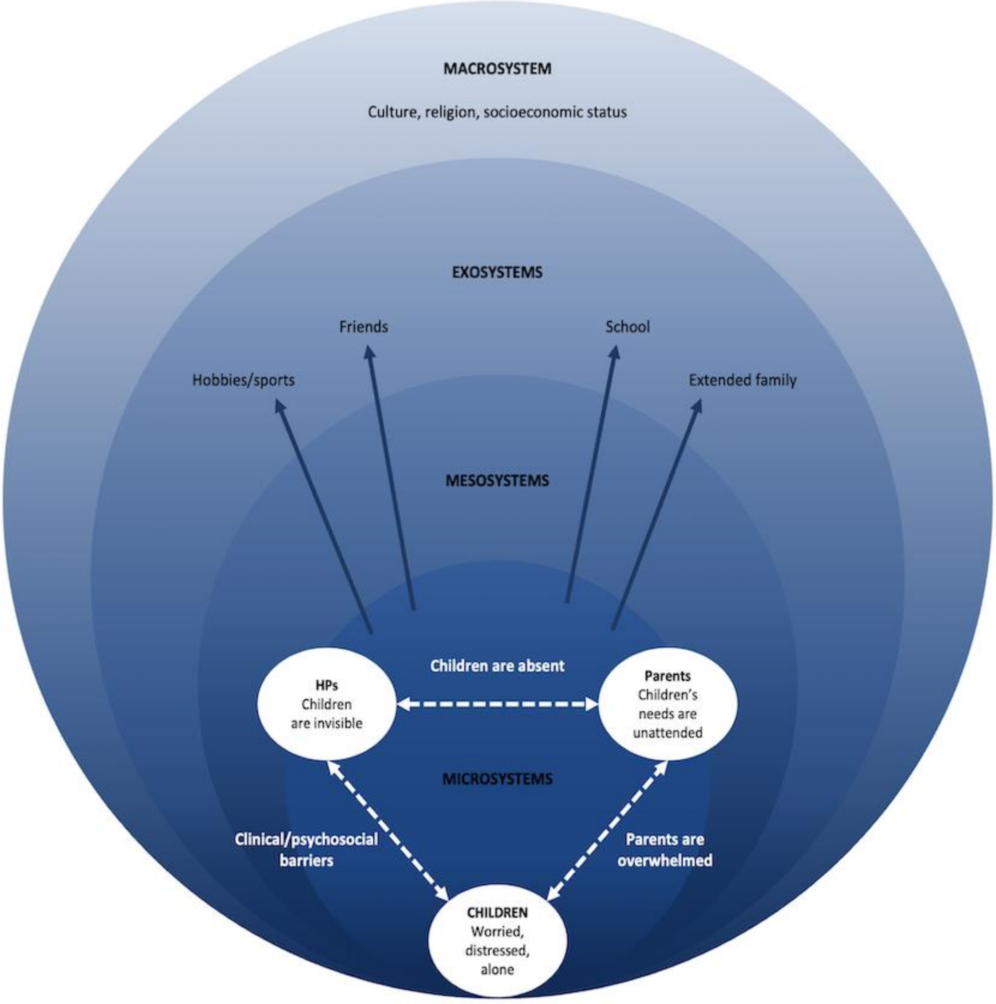

Figure 5. Alexander's Children's Cancer Communication (ACCC) model

Compromised social interactions and communication breakdowns

Children, parents, and HPs construct meaning through their social interactions with one another and their sharing of information (Blumer, 1969).

However, our findings indicated fundamental social interactions were not occurring, particularly between children and parents, and children and HPs. When a parent was diagnosed with cancer, dramatic changes were observed in children's micro-, meso, and exosystems which impacted the nature of these social interactions (Bronfenbrenner, 1996). For instance, parents' relationships with children were typically transformed and HPs were thrust into children's microsystems where their influence on children was directly felt. Also, children's pre-existing supports such as extended family, friends, school, and sports communities became less proximal. These changes were often unsupported, and this presented barriers which challenged children's meaningful interactions within these relationships.

Discussion

This study explored how children are affected by their parents' cancer diagnosis from multiple perspectives. Patients' children felt worried and distressed because they were alone in dealing with their complex thoughts, emotions, and experiences. Children's needs were often unattended because parents were overwhelmed by the diagnosis and children's visibility was reduced among HPs. These findings contribute to the growing body of parental cancer research by supporting current literature indicating there is significant disruption experienced by children which impacts their psychosocial wellbeing (Faccio et al., 2018; Walczak et al., 2018). Yet, parents parenting ability is often affected and they want clinical help supporting children's coping and developmental outcomes (Dalton et al., 2019; Dencker et al., 2019; Sinclair et al., 2019). However, fears and barriers render HPs reluctant to broach the subject of patients' children (Dalton et al., 2019; Dencker et al., 2019; Tafjord & Ytterhus, 2021). Our novel findings advance the literature by elucidating the underlying processes which contribute to these outcomes, and which have informed the development of our explanatory model.

Children felt confused about aspects of their parent's diagnosis, which is commonly reported in the literature (Fearnley & Boland, 2017; Walczak et al., 2018), suggesting their information and communication needs are not being met. Typically, when children are insufficiently informed they attempt to make sense of the diagnosis on their own, however, this is often fraught with misconceptions and magical thinking which exacerbates fears and heightens feelings of worry and distress (Dalton et al., 2019; Sinclair et al., 2019). Children in this study found it difficult to comprehend and articulate their thoughts and feelings, which impacted their capacity to effectively communicate with adults, indicating they need help with this process. However, findings in the parental cancer literature suggest parents assume higher communication quality than children (Weber et al., 2021) and underestimate children's information needs (Forrest et al., 2006). Furthermore, this reflects developmental literature reporting adults typically expect children to communicate at an adult level, and that the communication gap between adults and children needs to be more supported (Landreth, 2002). Open, timely, and age-appropriate communication is crucial to mitigating confusion and improving children's coping and adjustment to the diagnosis (Ellis et al., 2017; Phillips et al., 2021; Weber et al., 2021).

Parents felt overwhelmed by and struggled to understand the vast amount of information received about the diagnosis, which impacted their capacity to communicate with children. These findings reflect previous literature where parents commonly report their anxiety and uncertainty regarding how to provide ongoing and age-appropriate communication for children and are concerned for any harm they might cause (Dalton et al., 2019; Fearnley & Boland, 2017; Sinclair et al., 2019). Parents require clinician help with this process, yet this support is not routinely offered in healthcare (Fearnley & Boland, 2017; Sinclair et al., 2019). HPs are reluctant to broach the subject of children with patients (Dencker et al., 2019) and there are few empirically based resources (Alexander et al., 2019; Ohan et al., 2020). Communication interventions are methodologically weak (Alexander et al., 2019) and communication resources available through leading not-for-profit organisations are generally not empirically evaluated with sufficient rigor. Greater guidance and support is required to promote parent's ability to discuss their cancer diagnosis with children to ensure children's communication and information needs are met (Sinclair et al., 2019; Walczak et al., 2018).

Parents were further challenged to tend to children's information and communication needs due to being overwhelmed by the more practical and burdensome aspects of the cancer diagnosis. Parent-child communication is made increasingly difficult if parents are not mentally and physically capable. Similar to the current study, Sinclair and colleagues (2019) found that the impact of diagnosis and treatment effected the feasibility and accessibility of communication resources among mothers with breast cancer, and therefore, warranted careful consideration for how communication information is disseminated to parents. Significant upheaval and disruption when a parent is diagnosed with cancer is documented in the literature (Ghofrani et al., 2019; Sigal et al., 2003), however, our findings indicate practical support issues among families, remain unaddressed. Providing practical support around the challenges that come with a cancer diagnosis, such as the presence of a family support officer, would also enable parents to meet the communication and information needs of children.

Communication concerns with patients' children were also evident among HPs who were reluctant to approach children. Aligned with previous literature (Dalton et al., 2019; Dencker et al., 2019; Grant et al., 2016; Tafjord & Ytterhus, 2021; Turner et al., 2009), HPs in this study felt they were not educated or experienced enough in talking with children, which impacted their confidence and willingness to seek out children. This concern is not unfounded, as a patient's treating oncology team is primarily experienced in adult care and their interactions with children are minimal (Dalton et al., 2019; Dencker et al., 2019). However, there is evidence indicating parent's and children's desire for HPs to be communicating medical and clinical based information with children (Barnes et al., 2000; Fearnley & Boland, 2017; Kennedy & Lloyd-Williams, 2009). There appears to be limited empirical resources available to assist HPs with communicating with children (Dalton et al., 2019), except for a proposed communication framework by Semple and McCaughan (2019) and a communication tool by Hauken and Farbrot (2021). HPs are integral to supporting children's communication and information needs, hence, there is need for further education, training, and access to resources for HPs to ensure this is routinely occurring.

Clinical barriers prevented HPs from routinely identifying patients' children, yet HPs are well-positioned to support children (Fearnley & Boland, 2017; Tafjord & Ytterhus, 2021) and patients' children will likely benefit from these discussions (Ellis et al., 2017; Fitch & Abramson, 2007). Consistent with our findings, barriers such as time (Fearnley & Boland, 2017; King & Quill, 2006); opportunity (Dalton et al., 2019), and role (Ryan et al., 2005) are commonly reported in the healthcare literature. In this study children were also unlikely to approach HPs, consequently exacerbating the unlikeliness of HPs and children to interact and form meaningful relationships. Avoidance is common among children (Compas et al., 1996;

Krattenmacher et al., 2012) which therefore places an emphasis on HPs to be actively seeking out and engaging with children (Tafjord & Ytterhus, 2021). Web-based interventions for healthcare support, information, and therapeutic treatment are proving increasingly useful among children in other areas such as childhood cancer (Sansom-Daly et al., 2019; 2020) and mental health (Buttazzoni et al., 2021; Zeiler et al., 2021), and may address current problems experienced by HPs when supporting cancer patients' children (Tafjord & Ytterhus, 2021). These interventions are generally accessible, tailorable, less taxing on resources (e.g., HPs time), and well-received by young people (Boydell et al., 2014; Zeiler et al., 2021).

Breakdowns in communication and interaction are central components underlying how children are affected by parental cancer and therefore form the basis of our proposed model. The present study is the first to propose an empirically driven theoretical model that conceptualises how patients' children are affected by their parent's cancer diagnosis. One other study has proposed a causal model to potentially explain children's adjustment to a parent's cancer diagnosis (Su & Ryan-Wenger, 2007), however, this model was based on a review of the literature at that time. The model we propose, Alexander's Children's Cancer Communication (ACCC) model (Figure 5), provides a current explanation of how children are affected by their parents' cancer diagnosis, by integrating the latest evidence within the literature and incorporating our research findings. To date, most interventions for cancer patients' children have not produced clinically meaningful effects which may be attributed to limited methodological rigor (Niemelä et al., 2010; Ohan et al., 2020), including the absence of a theoretical foundation (Alexander et al., 2019). The ACCC model proposed in this study can be used to inform the development and implementation of future intervention strategies and therefore minimise the risk of Type III errors (i.e., rejection of the intervention when the intervention itself was inadequately designed and implemented) (Green, 2000; Wight et al., 2016). Furthermore, the ACCC model may be used to inform future clinical practice.

Clinical recommendations

Clinical and practical implications and recommendations derived from this study, which promote the timely support of cancer patients' children, are as follows:

- Training and education aimed at developing HPs communication skills and developmental knowledge.

- Development of a communication tool to be used by HPs to effectively communicate with patients' children. A new tool might also capture the benefits of technology and integrate the methods used in this study whereby children were encouraged to write and draw about their thoughts and feelings.
- Introducing routine and standardised screening processes for HPs to detect patients' children and efficiently refer them on to the appropriate supports and resources that are currently available. Oncology nurses may facilitate this approach while also being supported by the development of a new, or refinement of an existing, screening tool.
- Engaging a multidimensional approach to support parents with the practical challenges of a cancer diagnosis. For example, a family support worker or social worker who can assist families from diagnosis onwards.

Limitations

There was a gender bias as more female HPs participated in this study. However, this reflects the gendered nature of this industry (i.e., support professions) (Australian Beureau of Statistics [ABS], 2018; Sinclair et al., 2019). Male HPs may have had different perspectives, however, responses from participating male HPs were similar to those from females. HPs were recruited from one state (Western Australia) within Australia. While findings are consistent with studies from other jurisdictions it is acknowledged generalisability to other healthcare systems may be limited. There was a gender bias toward mothers, which is common in the parental cancer literature (Tavares et al., 2018). Fathers may have presented different perspectives, and future studies need to explore their perspectives. Parents and children were recruited through opt in methods and predominantly through cancer support services and a Comprehensive Cancer Centre. Therefore, it is likely the participants in this sample had greater psychological awareness and health literacy. This is commonly reported in similar studies (Beale et al., 2004; Bell & Ristovski-Slijepcevic, 2011; Bugge et al., 2009; Park et al., 2016), however, a sample from a more diverse background may be warranted. The age range of the children was broad; focusing on a narrower age range may have yielded different findings that reflect different experiences of children at different stages of development, and this could be considered in future studies.

Conclusion

Supporting cancer patients' children is becoming an urgent area of concern in psycho-oncological research and care. Our findings indicate when a parent is diagnosed with cancer, parents are unavailable to tend to their children's needs due to the demands associated with the cancer diagnosis, and HPs are challenged to provide the support that parents and children are asking for. Consequently, children are not seen and not heard by parents and HPs, and experience ongoing levels of heightened worry and distress as they feel alone in dealing with the diagnosis. The underlying mechanisms contributing to these findings are breakdowns in communication among children, parents, and HPs, additional to barriers that prevent them from interacting with each other. The findings from this study, including the proposed ACCC model which conceptualises how children are affected by their parent's diagnosis, can be used to inform future research by providing a theoretical foundation to inform future intervention development and evaluation.

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Supplementary Table 1.

Topic guide for qualitative interviews

Health Professionals

Number	Question	Prompts
1	Tell me about your contact and involvement with patients' children?	*Experiences*
2	What do children come in for? What do they talk about with you?	*What is life like for these children?* *What is going on for them?*
3	How do you feel patients' children are affected by their parents' cancer?	
4	What do you think would help patients and their children?	
5	What are your concerns for the wellbeing of patients' children?	
6	What supports do you feel children need to adjust to their parent's cancer diagnosis and treatment?	*Are these supports available*
7	Are patients' children supported in clinical practice?	*What supports are available?*
8	How might staff be assisted in providing support for children?	*How would you suggest these children could be better supported and assisted?*
9	Is there anything else you would like to say?	

Parents

Number	Question	Prompts
1	Can you tell me a bit about who is in your family?	*Such as who is in your family? Do you have any pets?*
2	What activities do you and your family enjoy doing together?	
3	Has any of this changed since your/your partner's diagnosis?	
4	Tell me about your cancer diagnosis	

5	What are the key challenges you have faced since your/your partner's diagnosis?	
6	Do you feel okay talking to your children about your/your partner's cancer and any changes?	*[If not]* Okay, why is that? *How have you talked to your children?*
7	How do you think your child/ren has/have been affected by your/your partner's cancer? How do you feel your child/ren has/have coped with your/your partner's cancer diagnosis?	
8	Have you noticed any other changes in your child's/children's behavior?	
9	What, if any, worries or concerns do you have for your child/ren and their coping with your/your partner's cancer?	
10	Do you feel confident and comfortable with supporting and assisting your child/ren to cope with your/your partner's cancer, and any problems or issues that might arise?	*What support have you had?*
11	Is there anything that might make you feel more comfortable to do this?	
12	What are the main challenges you face with supporting your child(ren)?	*Is there anything else you would like to say?*

Children

Number	Question	Prompts
1	Can you tell me about your family?	Such as who is in your family? Do you have any pets?
2	What are the fun things your family enjoy doing together?	Have any of these things changed lately?
3	Is there anything that you worry about?	
4	I was hoping you could tell me a little bit about your [mum/dad]. Has [mum/dad] been sick lately?	
5	What do you call [mum's/dad's] sick/sickness?	

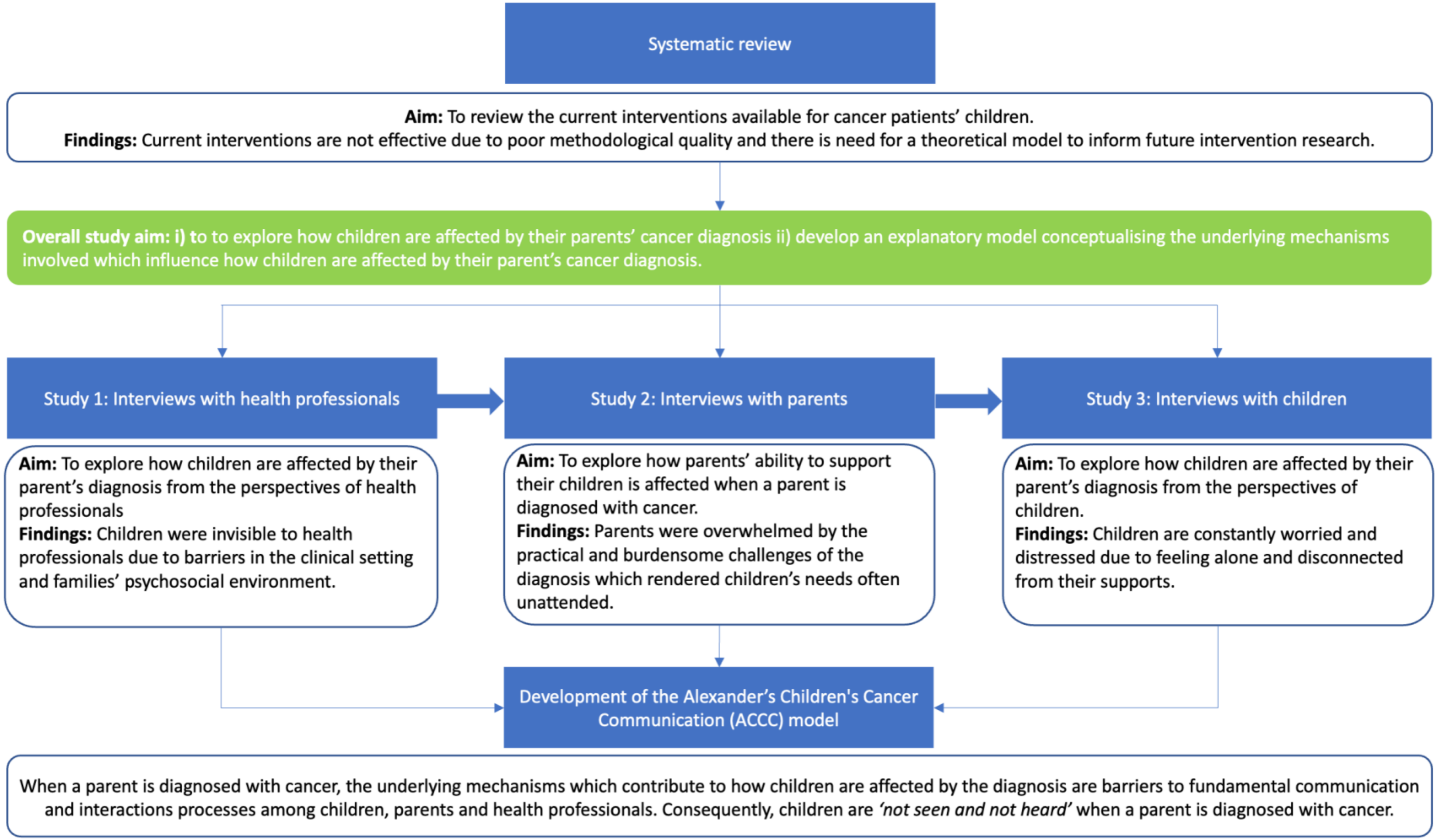
6	Tell me what you know about [mum’s/dad’s] sickness?	
7	If you have a question about [mum’s/dad’s] sickness, who do you ask or what do you do?	
8	Is mum and dad OK talking to you about [mum/dad] not being well?	*[If yes]* Tell me some of the things you talk about with mum and dad? *[If no]* Would you like to be able to talk to mum and dad about this more?
9	Are there more things you want to know about [mum’s/dad’s] sickness?	*[If yes]* Tell me what sort of things?
	What are some things you do to help you feel better about [mum/dad] not being well?	
	Has life been different since [mum/dad] found out [he/she] was not well?	*[If yes]* Tell me how it has been different?
	Are things still the same with your friends, or have they changed?	*[If they have changed]* Tell me how they have changed?
	Are things still the same at school, or have they changed?	*[If they have changed]* Tell me how they have changed?
	Is there someone at school you prefer to talk to about [mum/dad] not being well?	*[If yes]* Tell me who this person is?
	What makes you feel the happiest lately?	[Prompt] Activities? Things? Items? People?
	And, what makes you feel unhappy or sad lately?	[Prompt] Activities? Things? Items? People?
	If I asked you to do a special activity with mum or dad, and it could be any kind of activity, what would that special activity be?	
	If you had a friend that found out their mum or dad was not well in a similar way to your [mum/dad], what would you do to help that friend?	

CONCLUSION

This exploratory qualitative study aimed to determine how children with a parent with cancer are affected by their parent's cancer diagnosis (see Figure 1 for a visual overview of the research process). Initially, a general review of the literature discussed how families, parents, and children are affected by a parent's cancer diagnosis, and the context of clinical care and interventions that are available to support patients' children. This review led to the conclusion that there was need for a systematic review and full appraisal of current interventions available for cancer patients' children, to determine which interventions were effective with supporting children's psychosocial outcomes and the nature of these interventions including which mechanisms were effective and why. The findings from our systematic review indicated that current interventions for cancer patients' children were not effective at improving or reducing psychosocial outcomes among children (e.g., depression and anxiety), due to poor study quality including the absence of a relevant theory or model to guide intervention research. Therefore, based on these findings it was deemed necessary to empirically develop such a model which could be used to improve the methodological robustness of future intervention development and evaluation studies and promote the efficacy of interventions among cancer patients' children.

To achieve this objective, a comprehensive exploration into the effect a parent's cancer diagnosis has on their young children, from the perspectives of key informants, was conducted. An integrated theoretical approach combining symbolic interactionism (Blumer, 1969) and ecological systems theory (Bronfenbrenner, 1979) was adopted as this considered the high level of influence children's social interactions and their environment have on their developmental outcomes. In-depth, semi-structured interviews were conducted with oncology health professionals, parents/patients, and children using methods of constructivist grounded theory (Charmaz, 2006; 2014). These methods enabled the application of a flexible and co-constructive process to understanding participant's unique viewpoints of children's experiences, and the generation of a theoretical model which conceptualised the processes underlying how children are affected by their parent's diagnosis.

Findings from interviews with participants evidenced that when a parent was diagnosed with cancer, there were barriers in the clinical system and patients' psychosocial environment which challenged health professionals' ability to detect patients' children and ensure their timely referral for psychosocial and emotional support. Parents were often unavailable to tend to their children's needs due to being overwhelmed by the practical and more burdensome demands of their cancer diagnosis. Consequently, children felt disconnected from their supports and alone in dealing with their parent's diagnosis, which exacerbated their feelings of worry and distress. These barriers and challenges formed the underlying mechanisms that prevented fundamental interactions and communication processes from occurring among children, parents, and health professionals, which rendered children to be; *'not seen and not heard'* when their parent was diagnosed with cancer. As such, these findings informed the development of the Alexander's Children's Cancer Communication (ACCC) model, an explanatory model which conceptualises the underlying mechanisms involved that contribute to how children are affected by their parent's cancer diagnosis. This model demonstrates that when a parent is diagnosed with cancer, fundamental social interactions among children, parents, and health professionals are encumbered due to children's lack of visibility in the healthcare system and family life, which impacts communication processes between children, parents, and health professionals and leaves children unsupported. Furthermore, other supports such as extended family and friends are less accessible to children which further decreases their ability to be supported.



Systematic review

Aim: To review the current interventions available for cancer patients' children.
Findings: Current interventions are not effective due to poor methodological quality and there is need for a theoretical model to inform future intervention research.

Overall study aim: i) to to explore how children are affected by their parents' cancer diagnosis ii) develop an explanatory model conceptualising the underlying mechanisms involved which influence how children are affected by their parent's cancer diagnosis.

Study 1: Interviews with health professionals

Aim: To explore how children are affected by their parent's diagnosis from the perspectives of health professionals
Findings: Children were invisible to health professionals due to barriers in the clinical setting and families' psychosocial environment.

Study 2: Interviews with parents

Aim: To explore how parents' ability to support their children is affected when a parent is diagnosed with cancer.
Findings: Parents were overwhelmed by the practical and burdensome challenges of the diagnosis which rendered children's needs often unattended.

Study 3: Interviews with children

Aim: To explore how children are affected by their parent's diagnosis from the perspectives of children.
Findings: Children are constantly worried and distressed due to feeling alone and disconnected from their supports.

Development of the Alexander's Children's Cancer Communication (ACCC) model

When a parent is diagnosed with cancer, the underlying mechanisms which contribute to how children are affected by the diagnosis are barriers to fundamental communication and interactions processes among children, parents and health professionals. Consequently, children are *'not seen and not heard'* when a parent is diagnosed with cancer.

Figure 1. Research process

Suggestions for future research

This research poses a number of directions for future research, including the need for more methodologically robust intervention studies which adhere to the relevant reporting guidelines such as those outlined in the consolidated standards of reporting trials ([CONSORT], Moher, 2010) statement, to strengthen and clarify current research findings. Studies might also consider using the ACCC model proposed by this study to inform the development and evaluation of future interventions, to improve the study quality and rigor of intervention research and promote capacity for more targeted intervention among patients' children. More involvement of children is also required to inform and guide future research. As observed in the current study, children provide unique insight regarding their lived experiences, and it is imperative their voices are adequately heard and incorporated into the research. Moreover, participatory research involving children should endeavour to use more novel and developmentally appropriate techniques among children which supports children's comprehension and communication levels.

Findings from the current research study have also been used to propose a series of clinical recommendations, which include the need to develop a communication tool or resource for health professionals, to foster their ability to have more open and informative conversations with patients' children and provide psychosocial and emotional support. Such a resource might consider addressing this clinical need through the empirical development of a tool or resource that incorporates more developmentally informed techniques. Examples of these techniques include the novel approach used in the current study, or web-, application-, and gaming-based approaches, which have also proven feasible and effective in supporting children's mental health related to parental cancer (Piil et al., 2021) childhood cancer (Sansom-Daly et al., 2019; 2020) and other areas of child research (Buttazzoni et al., 2021; Sajeev et al., 2021; Zeiler et al., 2021).

Practice implications

The findings from this study also inform several practice implications at the individual, organisational, systems, and intersystem levels (Murell, 1970). At the individual level children report being alone and disconnected from fundamental supports including parents and health professionals. Consequently, their communication and information needs are not being met and children remain worried and distressed. According to Murell (1970) the processes that foster personality stability and change are a function of the interaction relationships between the individual and their environment. Therefore, the determinants of an individual's problems occur within their interaction relationships in their social systems. The findings of the current research study which are articulated in the proposed ACCC model, provide targeted areas (e.g., communication, information provision) for directing organisational and systemic changes (e.g., introducing standardised screening processes for identifying patients' children) aimed at improving children's interactions with parents and health professionals. Implementing these changes would increase the likeliness of fundamental communication processes between children and parents and health professionals to occur, thus also increasing the potential for children to receive the timely support they require. Recently, Piil and colleagues (2021) reported the theoretical and evidenced based development of electronic health games to facilitate the social interactions between parents with cancer and their children during hospitalisation. This is one such novel and developmentally informed approach to improving children's interactions with parents. Alternatively, our findings indicate parents are overwhelmed by the more burdensome aspects of the diagnosis which makes it difficult for parents to tend to their children's needs. Providing practical support for parents in the form of a family support worker would enable parents to be more present with children and ensure their needs are being met.

A family support worker could also serve to improve the likeliness of health professionals and children to interact with one another by ensuring the timely entry of children into clinical and healthcare systems, and that they are being detected by health professionals. Another means for promoting children's and health professionals' interactions is in the form of providing developmental education and information for health professionals. This would increase their confidence with talking to patients about their children and their likeliness to approach patients' children, thus promoting greater levels of holistic care for patients. Improving health professionals' knowledge of children could be further supported with a communication tool to assist health professionals with talking to patients' children (as proposed earlier). Further practice implications at the organisational and systemic level may include the development or refinement of a standardised screening tool or protocol for health professionals to be routinely detecting patients' children, thus ensuring children are efficiently entering the healthcare system and are appropriately referred on for support. Also, a comprehensive and detailed needs assessment which identifies and analyses the specific needs of children would increase the precision and unification of resource allocation decisions rather than addressing areas of broad need among patients' children.

Closing words

The effect a parent's cancer diagnosis has on their developing child is increasingly becoming an area of concern within psycho-oncological research and clinical care. Therefore, the current study addresses the observed paucity in the parental cancer literature by providing an in-depth insight of children's experiences when living with a parent with cancer from the perspectives of key informants, which included health professionals, parents, and children. The ACCC model proposed in this study can be used to inform future intervention development and evaluation studies thus improving the study quality and rigor of intervention research. Practice implications and clinical recommendations provided may be used to promote more targeted directions for improving holistic psycho-oncological care for cancer patients. This care would include safeguarding patients' children from being left alone to cope with their parent's diagnosis, thereby mitigating their vulnerability for ongoing, long-term psychosocial and behavioural effects elicited by the diagnosis.

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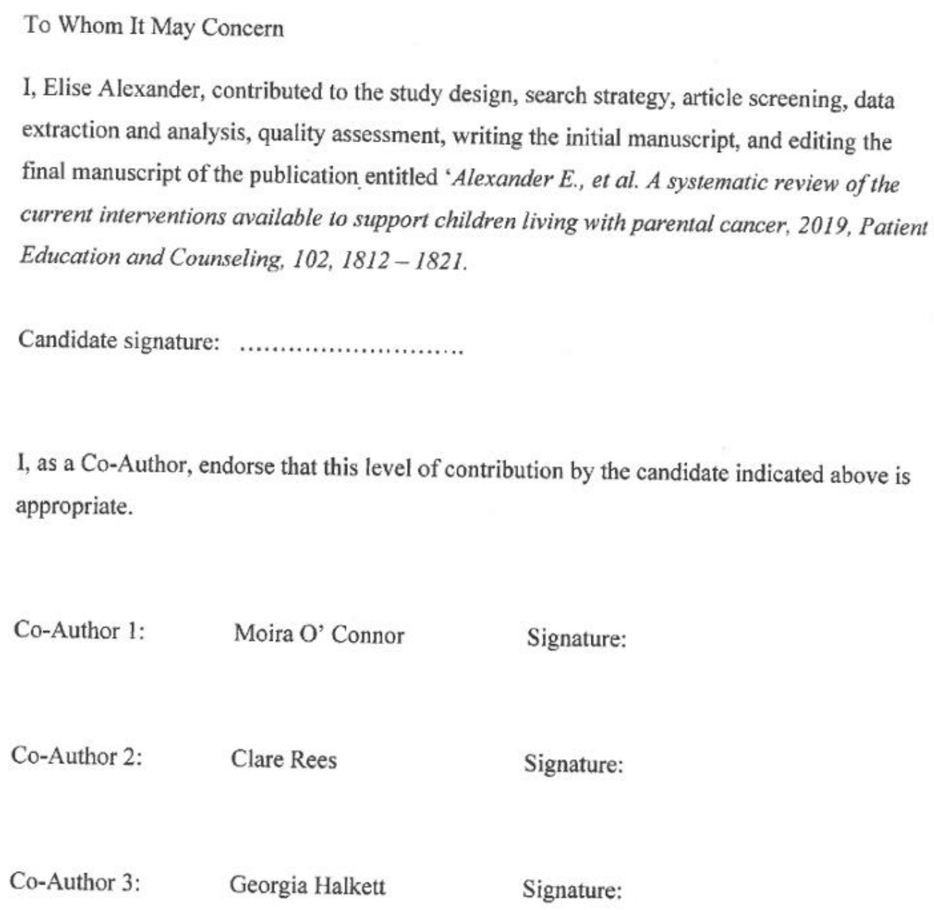
Appendices

Appendix A



To Whom It May Concern

I, Elise Alexander, contributed to the study design, search strategy, article screening, data extraction and analysis, quality assessment, writing the initial manuscript, and editing the final manuscript of the publication entitled '*Alexander E., et al. A systematic review of the current interventions available to support children living with parental cancer, 2019, Patient Education and Counseling, 102, 1812 – 1821.*

Candidate signature: ………………………..

I, as a Co-Author, endorse that this level of contribution by the candidate indicated above is appropriate.

Co-Author 1: Moira O' Connor Signature:

Co-Author 2: Clare Rees Signature:

Co-Author 3: Georgia Halkett Signature:

Appendix B

To Whom It May Concern

I, Elise Alexander, contributed to the study design, data collection and analysis, quality assessment, writing the initial manuscript, and editing the final manuscript of the publication entitled ‘*Alexander E., et al. The perceived effect of parental cancer on children still living at home: According to oncology health professionals, 2020, European Journal of Cancer Care, 29.*

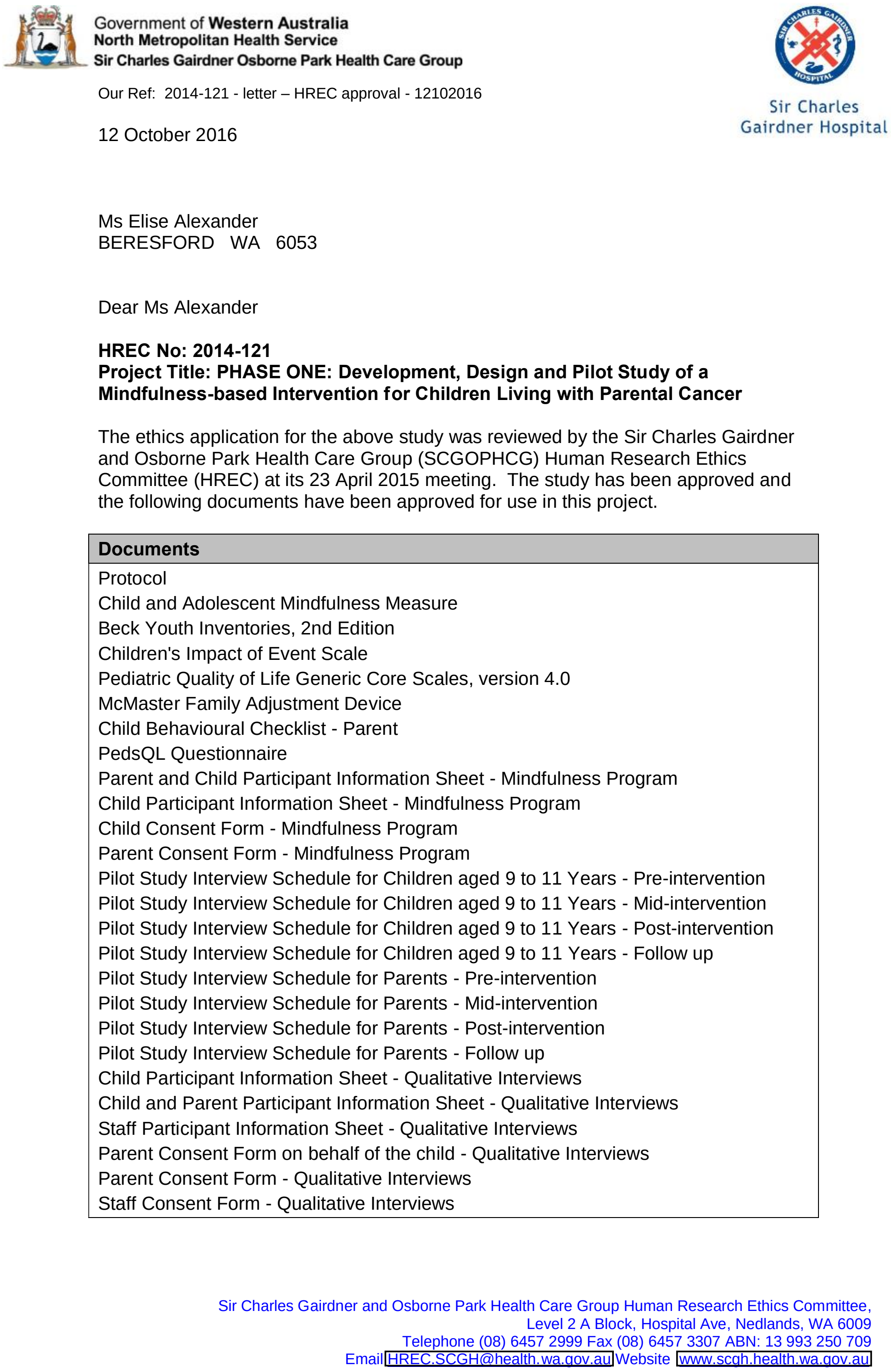
Candidate signature: ……………………..

I, as a Co-Author, endorse that this level of contribution by the candidate indicated above is appropriate.

Co-Author 1:	Moira O’ Connor	Signature:
Co-Author 2:	Georgia Halkett	Signature:

Appendix C

HREC approval letter



Government of **Western Australia**
North Metropolitan Health Service
Sir Charles Gairdner Osborne Park Health Care Group

Sir Charles
Gairdner Hospital

Our Ref: 2014-121 - letter – HREC approval - 12102016

12 October 2016

Ms Elise Alexander
BERESFORD WA 6053

Dear Ms Alexander

HREC No: 2014-121
Project Title: PHASE ONE: Development, Design and Pilot Study of a Mindfulness-based Intervention for Children Living with Parental Cancer

The ethics application for the above study was reviewed by the Sir Charles Gairdner and Osborne Park Health Care Group (SCGOPHCG) Human Research Ethics Committee (HREC) at its 23 April 2015 meeting. The study has been approved and the following documents have been approved for use in this project.

Documents
Protocol
Child and Adolescent Mindfulness Measure
Beck Youth Inventories, 2nd Edition
Children's Impact of Event Scale
Pediatric Quality of Life Generic Core Scales, version 4.0
McMaster Family Adjustment Device
Child Behavioural Checklist - Parent
PedsQL Questionnaire
Parent and Child Participant Information Sheet - Mindfulness Program
Child Participant Information Sheet - Mindfulness Program
Child Consent Form - Mindfulness Program
Parent Consent Form - Mindfulness Program
Pilot Study Interview Schedule for Children aged 9 to 11 Years - Pre-intervention
Pilot Study Interview Schedule for Children aged 9 to 11 Years - Mid-intervention
Pilot Study Interview Schedule for Children aged 9 to 11 Years - Post-intervention
Pilot Study Interview Schedule for Children aged 9 to 11 Years - Follow up
Pilot Study Interview Schedule for Parents - Pre-intervention
Pilot Study Interview Schedule for Parents - Mid-intervention
Pilot Study Interview Schedule for Parents - Post-intervention
Pilot Study Interview Schedule for Parents - Follow up
Child Participant Information Sheet - Qualitative Interviews
Child and Parent Participant Information Sheet - Qualitative Interviews
Staff Participant Information Sheet - Qualitative Interviews
Parent Consent Form on behalf of the child - Qualitative Interviews
Parent Consent Form - Qualitative Interviews
Staff Consent Form - Qualitative Interviews

Sir Charles Gairdner and Osborne Park Health Care Group Human Research Ethics Committee,
Level 2 A Block, Hospital Ave, Nedlands, WA 6009
Telephone (08) 6457 2999 Fax (08) 6457 3307 ABN: 13 993 250 709
Email HREC.SCGH@health.wa.gov.au Website www.scgh.health.wa.gov.au

Appendix D

Participant information and consent forms

Sir Charles Gairdner Hospital

Information Sheet for Staff

Qualitative Interviews

(Research study conducted by Curtin University)

Lay Title: The experiences of children with a parent with cancer

Study Title: Conceptualising the Experiences of Children Living with Parental Cancer - A Grounded Theory Approach.

Dear Member of Staff

My name is Elise Alexander and I am currently a Doctor of Philosophy (Clinical Psychology) student enrolled at Curtin University. I would like to take this opportunity to invite yourself and your child to take part in a study that I am conducting as part of my PhD thesis.

Research Purpose

The purpose of this research study is to unpack and conceptualise how children living with a parent with cancer are affected by their parent's cancer diagnosis and treatment.

Participation Requirement

Participation in this study requires that you are experienced in providing health care to patients with cancer whom have a child or adolescent living at home.

The Research Study

You will be invited to take part in a relaxed interview with me of approximately 30 minutes. The interview is designed to establish how you feel patients' children are affected by parental cancer. While this interview will be audiotaped, recordings may be paused at any point should there be a need to. Recordings will then be transcribed by me, and only my supervisors and I will hear these recordings. Any identifying information will be kept separate to transcriptions, and recordings will be permanently deleted at the end of transcribing. Your answers will then be used to write a report concerning how children are affected by parental cancer, and to inform the development of an intervention designed to assist these children. While the information you have provided might be included in the report, your name and any other identifying material will be excluded. You will also be reimbursed for your time with a $15 gift voucher.

Potential Risks

While efforts have been undertaken to minimise potential discomfort, should you feel uncomfortable at any point, then the interview may be stopped and resumed if and when ready. The appropriate supports can also be arranged should you feel it necessary for you to speak with someone.

Confidentiality and Anonymity:

At all times, your confidentiality and anonymity will be maintained. All information collected will be kept in a locked filing cabinet at Curtin University and in password protected files on my computer. Only my supervisors and myself will have access to this information.

Withdrawal from the Study:

Your participation is completely voluntary. Should you wish to discontinue with participation for whatever reason, at any point across the study, this will be respected.

Ethical Considerations

The Human Research Ethics Committee at Curtin University (Approval Number EC00271) and the Ethics Committee at Sir Charles Gardiner Hospital have approved the present study. This study will be conducted in accordance with the guidelines stipulated by the National Statement on Ethical Conduct in Research Involving Humans (NHMRC).

Further Information

If you require further information, or would like to take part in this study, please feel welcome to contact me via:

Phone: 0497 846 880, or
Email: elise.alexander@postgrad.curtin.edu.au

Alternatively, you may contact my supervisors:

Dr, Moira O'Connor
Phone: 9266 3450
Email: M.Oconnor@curtin.edu.au

or

Associate Professor Clare Rees
Phone: 9266 2464
Email: C.Rees@curtin.edu.au

This research has been reviewed by the Sir Charles Gairdner Group (SCGG) Human Research Ethics Committee. This research has also been approved by the Human Research Ethics Committee at Curtin University.

However, should you wish to discuss the ethical aspects of this research, please contact:

The Executive Officer of the Human Research Ethics Committee office at Sir Charles Gairdner Hospital:
Ph: 9346 2999
Email: SCGH.HREC@health.wa.gov.au

OR

The Secretary of the Human Research Ethics Committee at Curtin University
Ph: (08) 9266 2784
Email: hrec@curtin.edu.au

Sir Charles Gairdner Hospital

Consent Form for Staff

Qualitative Interviews

(Research study conducted by Curtin University)

Lay Title: ***The experiences of children with a parent with cancer***

Study Title: ***Conceptualising the Experiences of Children Living with Parental Cancer - A Grounded Theory Approach.***

I ____ have read the attached Participant Information Sheet, and any questions that I have asked have been appropriately answered to my satisfaction.

I understand the purposes, procedures and risks of the research described in the project.

I agree to taking part in the outlined study, however I am aware that my participation is strictly voluntary and I may withdraw for any reason and at any point in time, without ramification or prejudice.

I acknowledge that all personal details and information will remain confidential and will not be released by the primary researcher without my permission, or unless this person is required to do so by law.

I am of full understanding that the findings derived from this study will be used by the primary researcher to develop and trial a proposed intervention for children with a parent with cancer.

Signature ______________________________ Date ____________________
(Participant)

Signature ______________________________ Date ____________________
(Researcher, Elise Alexander)

Signature ______________________________ Date ____________________
(Supervisor, Dr. Moira O'Connor)

This research has been reviewed by the Sir Charles Gairdner Group (SCGG) Human Research Ethics Committee. This research has also been approved by the Human Research Ethics Committee at Curtin University.

However, should you wish to discuss the ethical aspects of this research, please contact:

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OR

The Secretary of the Human Research Ethics Committee at Curtin University
Ph: (08) 9266 2784
Email: hrec@curtin.edu.au

Participants are to receive a copy of the Information Sheet for Patient and Patient Consent Form for their personal record.

Curtin University

Sir Charles Gairdner Hospital

Information Sheet for Parents/Caregivers

Qualitative Interviews

(Research study conducted by Curtin University)

Lay Title: *The experiences of children with a parent with cancer*

Study Title: *Conceptualising the Experiences of Children Living with Parental Cancer - A Grounded Theory Approach.*

Dear Parent/Caregiver

My name is Elise Alexander and I am currently a Doctor of Philosophy (Clinical Psychology) student enrolled at Curtin University. I would like to take this opportunity to invite yourself and your child to take part in a study that I am conducting as part of my PhD thesis.

Research Purpose

The purpose of this research study is to determine how children with a parent with cancer are affected by their parent's cancer diagnosis and treatment, in addition to how a proposed intervention program designed to assist patients' children, might look.

Participation Requirement

Participation in this study requires that you have a child whom is currently living at home with you.

The Research Study

You and your child will be invited to take part in separate interviews of approximately 30 minutes to be facilitated by me. The interviews are designed to establish how each of you feel children are affected by their parent's cancer. While this interview will be audiotaped, recordings may be paused at any point should there be a need to. Recordings will then be transcribed by me, and only my supervisors and I will hear these recordings. Any identifying information will be kept separate to transcriptions, and recordings will be permanently deleted at the end of transcribing. Your answers will then be used to write a report concerning how children are affected by parental cancer and to develop a model of understanding regarding how children are impacted by their parent's cancer diagnosis. While the information you have provided might be included in the report, your names and any other identifying material will be excluded. You and your child will also be reimbursed for your time with a $15 gift voucher.

Potential Risks

Developmental considerations have been undertaken to ensure that children's interviews are child-friendly, sensitive and non-confrontational. If either you or your child feels uncomfortable or upset at any point, then the interview may be stopped and resumed when ready. The appropriate supports can also be arranged should you feel it necessary for you or your child to speak with someone.

Confidentiality and Anonymity:

At all times, confidentiality regarding both yourself and your child will be maintained. All information collected will be kept in a locked filing cabinet at Curtin University and in password protected files on my computer. Only my supervisors and myself will have access to this information.

Withdrawal from the Study:

Your participation and your child's participation is completely voluntary. Should either of you wish to discontinue with participation for whatever reason, at any point across the study, then this will be respected.

Ethical Considerations

The Human Research Ethics Committee at Curtin University (Approval Number EC00271) and the Sir Charles Gairdner Group Research Ethics Committee have approved this study. This study will be conducted in accordance with the guidelines stipulated by the National Statement on Ethical Conduct in Research Involving Humans (NHMRC).

Further Information

If you require further information, or would like to take part in this study, please feel welcome to contact me via:

Phone: 0497 846 880, or
Email: elise.alexander@postgrad.curtin.edu.au

Alternatively, you may contact my supervisors:

Associate Professor Moira O'Connor
Phone: 9266 3450
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or

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OR

The Secretary of the Human Research Ethics Committee at Curtin University
Ph: (08) 9266 2784
Email: hrec@curtin.edu.au

Curtin University

Sir Charles Gairdner Hospital

Consent Form for Parent

<u>Qualitative Interviews</u>

(Research study conducted by Curtin University)

Lay Title: ***The experiences of children with a parent with cancer***

Study Title: ***Conceptualising the Experiences of Children Living with Parental Cancer - A Grounded Theory Approach.***

I ____ have read the attached Participant Information Sheet, and any questions that I have asked have been appropriately answered to my satisfaction.

I understand the purposes, procedures and potential risks of the research described in the project.

I agree to taking part in the outlined study, however I am aware that my participation is strictly voluntary and I may withdraw for any reason and at any point in time, without ramification or prejudice.

I acknowledge that all personal details and information will remain confidential and will not be released by the primary researcher without my permission, or unless this person is required to do so by law.

I am of full understanding that the findings derived from this study will be used by the primary researcher to understand how children are affected by their parent's cancer diagnosis and may be used in the future to develop and trial a proposed intervention for these children.

Signature ______________________________ Date ____________________
(Participant)

Signature ______________________________ Date ____________________
(Researcher, Elise Alexander)

Signature ______________________________ Date ____________________
(Supervisor, A/Prof. Moira O'Connor)

This research has been reviewed by the Sir Charles Gairdner Group (SCGG) Human Research Ethics Committee. This research has also been approved by the Human Research Ethics Committee at Curtin University.

However, should you wish to discuss the ethical aspects of this research, please contact:

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OR

The Secretary of the Human Research Ethics Committee at Curtin University
Ph: (08) 9266 2784
Email: hrec@curtin.edu.au

Participants are to receive a copy of the Information Sheet for Patient and Patient Consent Form for their personal record.

Sir Charles Gairdner Hospital

Consent Form for Parent/Guardian - on behalf of the child

Qualitative Interviews

(Research study conducted by Curtin University)

Lay Title: ***The experiences of children with a parent with cancer***
Study Title: ***Conceptualising the Experiences of Children Living with Parental Cancer - A Grounded Theory Approach.***

I ____ have read the attached Participant Information Sheet, and any questions that I have asked have been appropriately answered to my satisfaction.

I acknowledge that my child and I understand the purposes, procedures and potential risks described in the study, and we are now able to make an informed decision to allow my child to participate in this study.

On behalf of my child ______________________________, I agree to the following.

My child may take part in the outlined study; however they are aware that their participation is strictly voluntary and they may withdraw for any reason and at any point in time, without ramification or prejudice.

My child is aware that all personal details and information will remain confidential and will not be released by the primary researcher without their permission, or unless this person is required to do so by law.

My child is of full understanding that the findings derived from this study will be used by the primary researcher to develop and trial a proposed intervention for children with a parent with cancer.

Signature ______________________________ Date ____________________
(Parent, on the behalf of their child)

Signature ______________________________ Date ____________________
(Researcher, Elise Alexander)

Signature ______________________________ Date ____________________
(Supervisor, A/Prof. Moira O'Connor)

Verbal assent has been received from the child.

Signature ______________________________ Date ____________________
(Researcher, Elise Alexander)

This research has been reviewed by the Sir Charles Gairdner Group (SCGG) Human Research Ethics Committee. This research has also been approved by the Human Research Ethics Committee at Curtin University.

However, should you wish to discuss the ethical aspects of this research, please contact:

The Executive Officer of the Human Research Ethics Committee office at Sir Charles Gairdner Hospital:
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Email: hrec@curtin.edu.au

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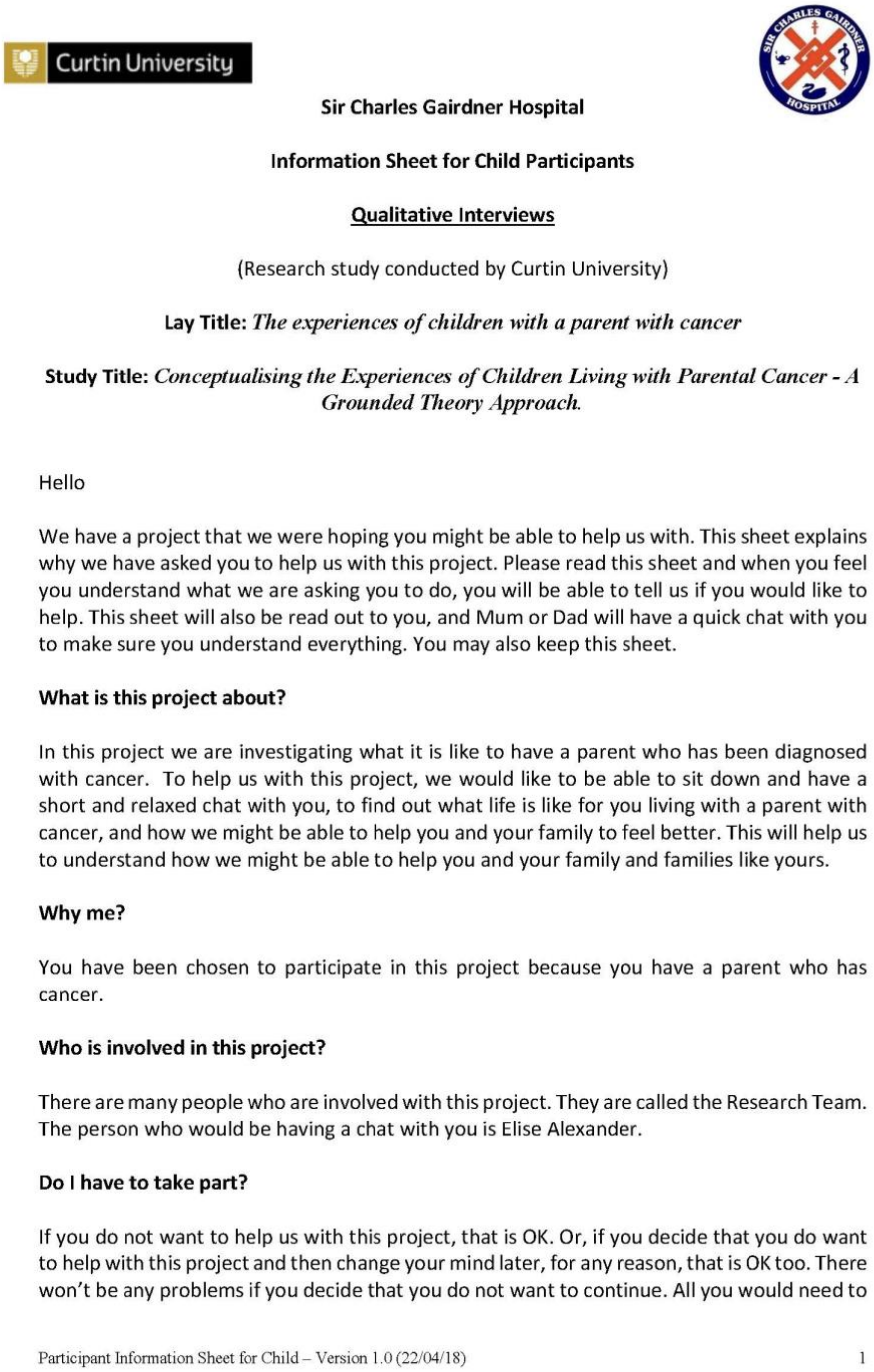
Appendix E

Information sheet for children



Curtin University

Sir Charles Gairdner Hospital

Information Sheet for Child Participants

<u>Qualitative Interviews</u>

(Research study conducted by Curtin University)

Lay Title: *The experiences of children with a parent with cancer*

Study Title: *Conceptualising the Experiences of Children Living with Parental Cancer - A Grounded Theory Approach.*

Hello

We have a project that we were hoping you might be able to help us with. This sheet explains why we have asked you to help us with this project. Please read this sheet and when you feel you understand what we are asking you to do, you will be able to tell us if you would like to help. This sheet will also be read out to you, and Mum or Dad will have a quick chat with you to make sure you understand everything. You may also keep this sheet.

What is this project about?

In this project we are investigating what it is like to have a parent who has been diagnosed with cancer. To help us with this project, we would like to be able to sit down and have a short and relaxed chat with you, to find out what life is like for you living with a parent with cancer, and how we might be able to help you and your family to feel better. This will help us to understand how we might be able to help you and your family and families like yours.

Why me?

You have been chosen to participate in this project because you have a parent who has cancer.

Who is involved in this project?

There are many people who are involved with this project. They are called the Research Team. The person who would be having a chat with you is Elise Alexander.

Do I have to take part?

If you do not want to help us with this project, that is OK. Or, if you decide that you do want to help with this project and then change your mind later, for any reason, that is OK too. There won't be any problems if you decide that you do not want to continue. All you would need to do is tell Mum or Dad (or another person who cares for you) and they can call Elise on 0497 846 880.

What do I have to do?

To help us with this project, Elise would like to be able to have a chat with you and ask you some questions about what it is like having a parent who has been diagnosed with cancer, and what are some things that might help you and your family to feel better. She will be recording this to help her remember what you say, but the recorder can be turned of at any point if you ask her to. This chat would last for around 20 to 30 minutes.

Elise will then type out what has been recorded during your chat. She will not write your name down. Only Elise and the research team will hear the tape. When Elise has finished typing out your chat, the tape will be wiped so that your words will disappear. The typed words will be stored on our computers but not your name.

How will this help me?

We might not be able to help make things easier for you and your family right now, but what you tell us might help us to help other children who find out their parent has cancer.

What are the possible problems?

We don't think that our chat will upset you, but if you do find it upsetting then there are people who can talk to you. You just need to tell Elise and we will help you talk to someone.

What happens when our chat is over?

When our chat is over, you will be given a gift voucher to thank you for helping us. When Elise has spoken to some other people, including children like you, all of their answers will help us to understand and write about how we might be able to help children who also have a parent with cancer.

Will my taking part in this project be kept a secret?

When Elise writes her report she might include some of the things that you have said. But, your name will not be mentioned in this report, so no one will know what you have said to Elise. If you do decide to help us with this project, we will not tell anyone what you say to Elise, unless we feel someone such as Mum or Dad, needs to know you need a little extra help with things.

Permission ('ethical approval') from Curtin University

Our university (which is like your school) and your parent's hospital have said that it is OK for us to talk to you and do our project. This is called ethical approval. It is like getting permission from someone to do something important, and to make sure it is done correctly.

Curtin University Human Research Ethics Committee and Sir Charles Gairdner Group Human Research Ethics Committee have given approval for this project.

Do you have any other question?

If you would like to be able to ask us any other questions about helping us with this project – or if your parents would like to ask, you can contact Elise Alexander on 0497 846 880.

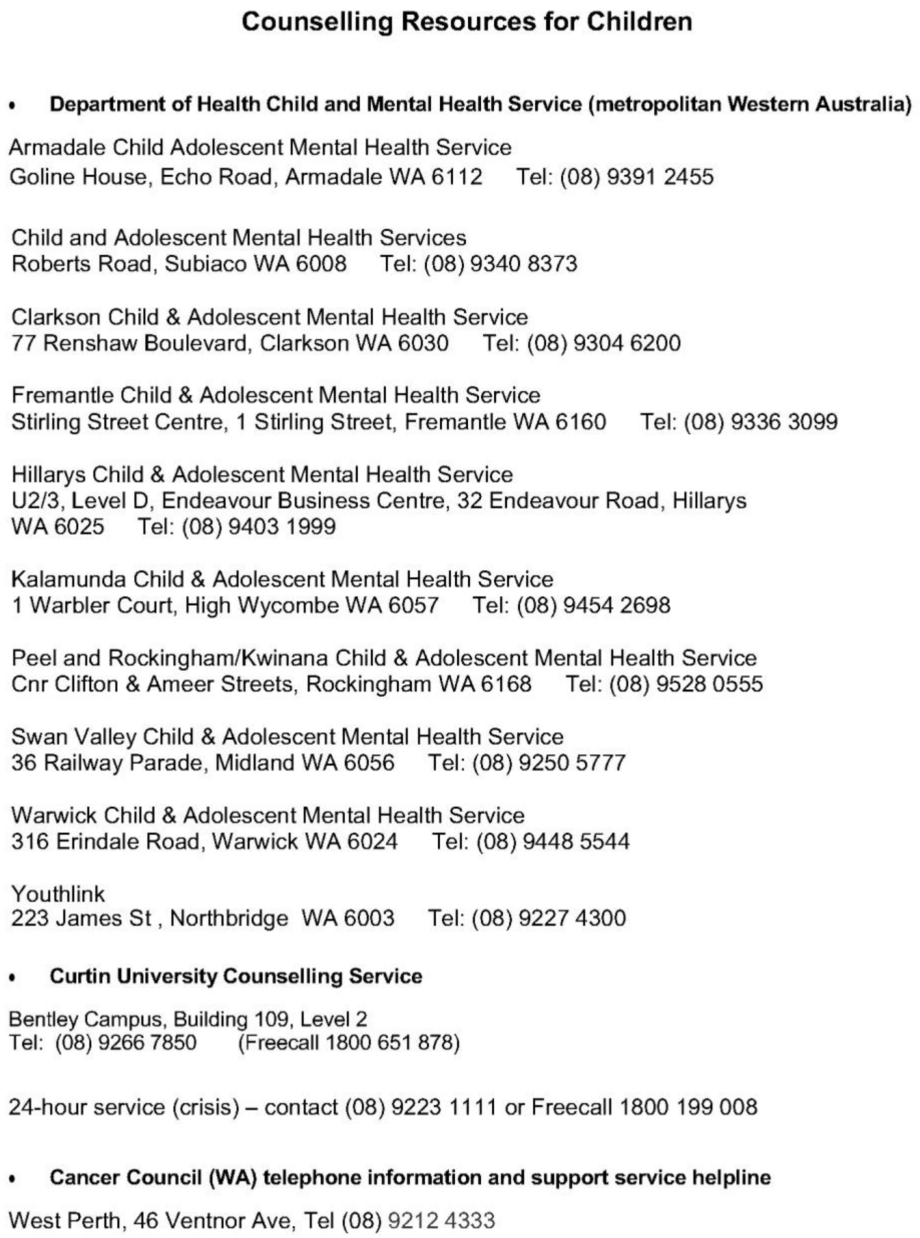
Thank you for reading this. It will now be read out to you, and Mum or Dad will also have a quick chat with you, just to make sure you understand.

Would you like to help?

Once Mum or Dad has had a talk with you, and you feel you know what this project is about please tell me if you would like to help me with this project, or not. Remember, it is OK if you decide you do not want to ☺

Appendix F

Counselling Support Lists



Counselling Resources for Children

- **Department of Health Child and Mental Health Service (metropolitan Western Australia)**

Armadale Child Adolescent Mental Health Service
Goline House, Echo Road, Armadale WA 6112   Tel: (08) 9391 2455

Child and Adolescent Mental Health Services
Roberts Road, Subiaco WA 6008   Tel: (08) 9340 8373

Clarkson Child & Adolescent Mental Health Service
77 Renshaw Boulevard, Clarkson WA 6030   Tel: (08) 9304 6200

Fremantle Child & Adolescent Mental Health Service
Stirling Street Centre, 1 Stirling Street, Fremantle WA 6160   Tel: (08) 9336 3099

Hillarys Child & Adolescent Mental Health Service
U2/3, Level D, Endeavour Business Centre, 32 Endeavour Road, Hillarys
WA 6025   Tel: (08) 9403 1999

Kalamunda Child & Adolescent Mental Health Service
1 Warbler Court, High Wycombe WA 6057   Tel: (08) 9454 2698

Peel and Rockingham/Kwinana Child & Adolescent Mental Health Service
Cnr Clifton & Ameer Streets, Rockingham WA 6168   Tel: (08) 9528 0555

Swan Valley Child & Adolescent Mental Health Service
36 Railway Parade, Midland WA 6056   Tel: (08) 9250 5777

Warwick Child & Adolescent Mental Health Service
316 Erindale Road, Warwick WA 6024   Tel: (08) 9448 5544

Youthlink
223 James St , Northbridge WA 6003   Tel: (08) 9227 4300

- **Curtin University Counselling Service**

Bentley Campus, Building 109, Level 2
Tel: (08) 9266 7850   (Freecall 1800 651 878)

24-hour service (crisis) – contact (08) 9223 1111 or Freecall 1800 199 008

- **Cancer Council (WA) telephone information and support service helpline**

West Perth, 46 Ventnor Ave, Tel (08) 9212 4333

Cancer Council Helpline - 13 11 20

- **Kids Helpline**

24 hour a day, 7 days a week counselling service for kids and young people aged 5-25years (Freecall 1800 55 1800)

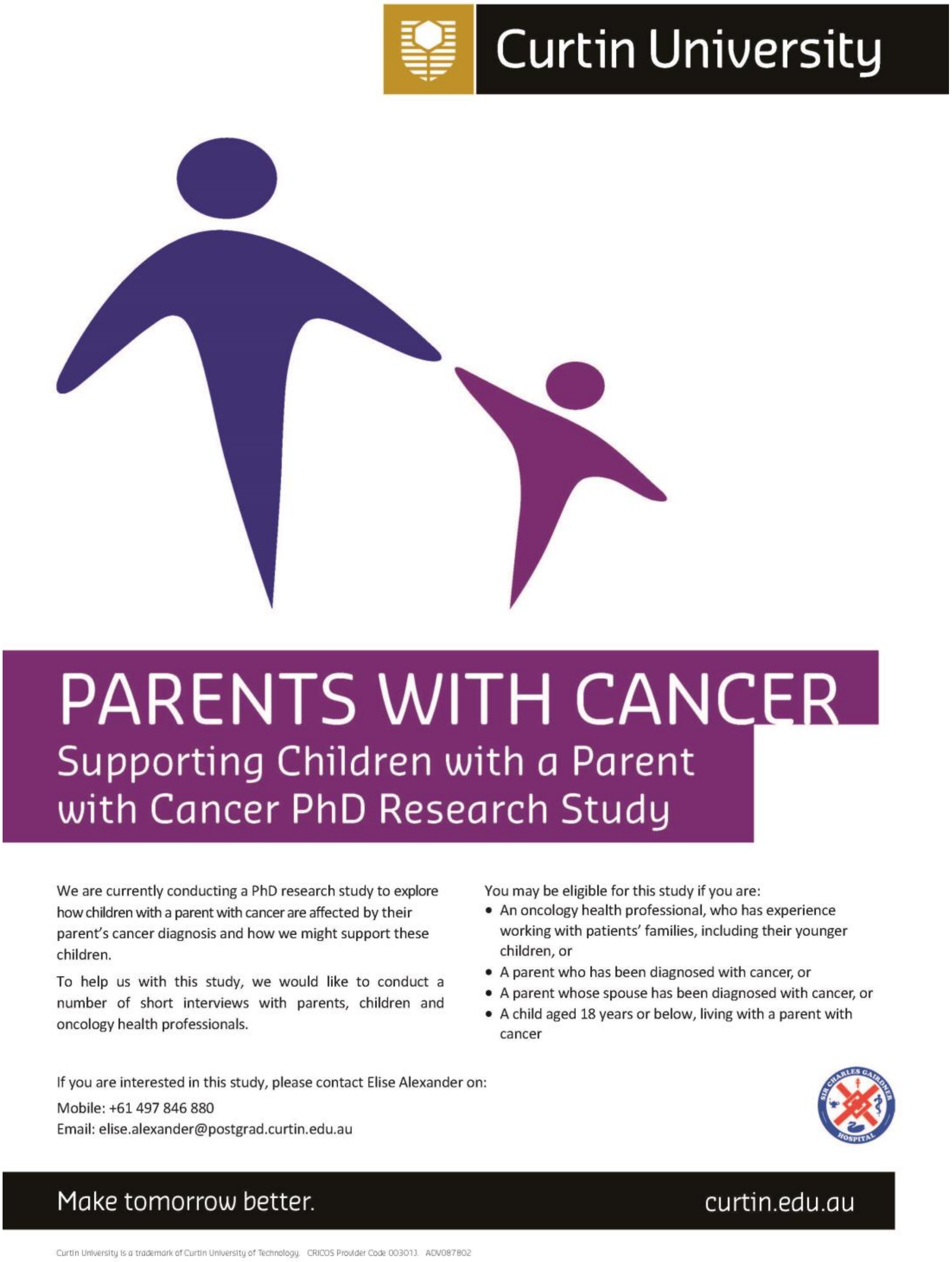
- **Canteen**

National support organisation for young people living with cancer, for 12-24 year olds whoare living with cancer (including having an immediate family member who has cancer) -

Western Australia - A H Crawford Lodge, 55 Monash
Ave, Nedlands,Tel (08) 9287 5111

Appendix G

Fliers



Curtin University

PARENTS WITH CANCER

Supporting Children with a Parent with Cancer PhD Research Study

We are currently conducting a PhD research study to explore how children with a parent with cancer are affected by their parent's cancer diagnosis and how we might support these children.

To help us with this study, we would like to conduct a number of short interviews with parents, children and oncology health professionals.

You may be eligible for this study if you are:

- An oncology health professional, who has experience working with patients' families, including their younger children, or
- A parent who has been diagnosed with cancer, or
- A parent whose spouse has been diagnosed with cancer, or
- A child aged 18 years or below, living with a parent with cancer

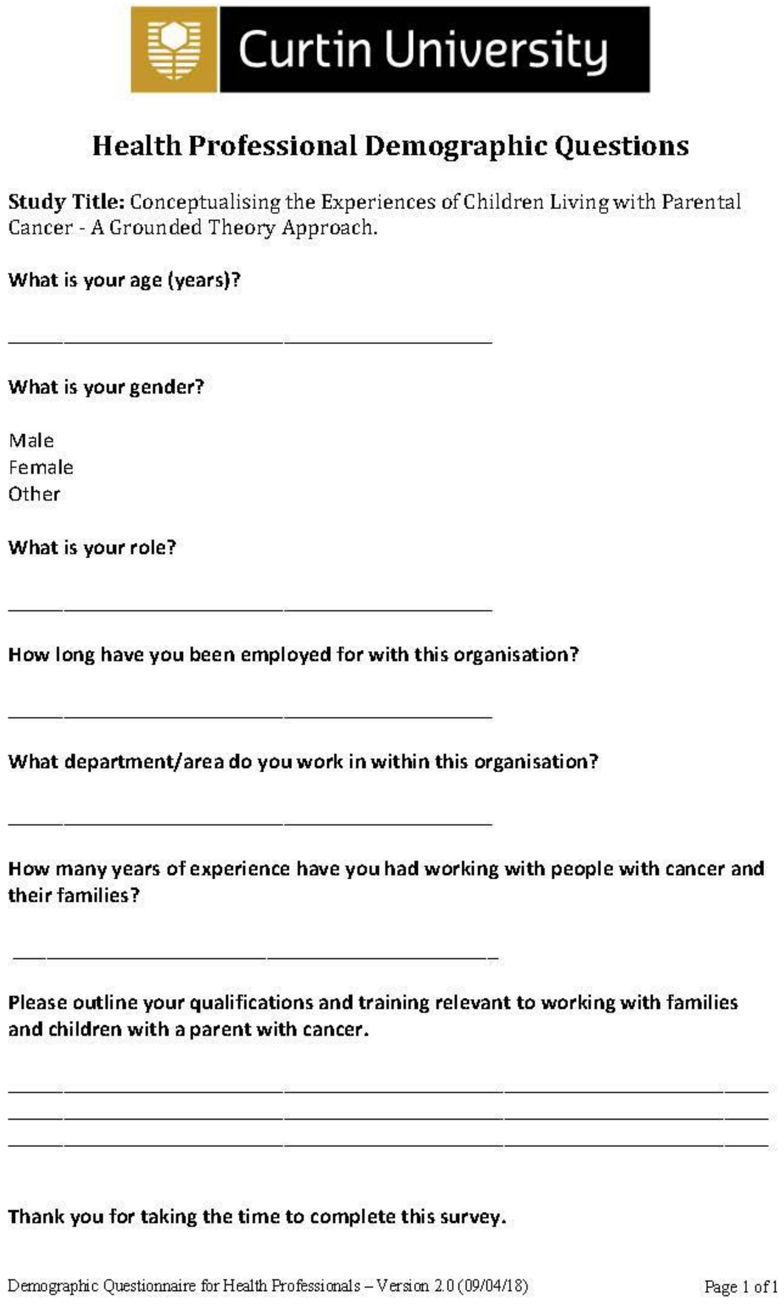
If you are interested in this study, please contact Elise Alexander on:

Mobile: +61 497 846 880
Email: elise.alexander@postgrad.curtin.edu.au

Make tomorrow better.   curtin.edu.au

Appendix H

Participant demographics



Curtin University

Health Professional Demographic Questions

Study Title: Conceptualising the Experiences of Children Living with Parental Cancer - A Grounded Theory Approach.

What is your age (years)?

____

What is your gender?

Male
Female
Other

What is your role?

____

How long have you been employed for with this organisation?

____

What department/area do you work in within this organisation?

____

How many years of experience have you had working with people with cancer and their families?

____

Please outline your qualifications and training relevant to working with families and children with a parent with cancer.

____
____
____

Thank you for taking the time to complete this survey.

Demographic Questionnaire for Health Professionals – Version 2.0 (09/04/18)

Curtin University

Parent and Child Demographic Questions

Study Title: ***Conceptualising the Experiences of Children Living with Parental Cancer - A Grounded Theory Approach.***

Parents

What is your age?

____

What is your gender?

Male
Female
Other

What is the highest level of education you have completed?

Completed some high school
High school graduate
Tertiary degree
Postgraduate degree
Other, please specify

____

What is your current marital status?

Single (never married)
De facto
Married
Separated
Divorced
Widowed
Would rather not say

What is your primary spoken language at home?

English
Other, please specify

____

In which country were you born?

Australia
Indigenous or Torres Strait Islander
Other, please specify

____

In which country were your parents born?

____

Are you of Aboriginal or Torres Strait Islander origin?

Yes
No

Please outline the age and gender of the children currently living at home with you.

Child 1: ____

Child 2: ____

Child 3: ____

Child 4: ____

____
____
____

What (if any) sports and hobbies are you involved with?

If you do not know the answers to any of the following questions, please leave these blank.

May we have permission to check the answer to any unanswered questions with your nurse?

Yes
No

If yes, could you please tell us the name of your nurse, and where in the hospital they are based?

Who is the person diagnosed with cancer?

You
Your spouse/partner

Please state the primary cancer diagnosis.

Please state any secondary cancers.

Please state the stage of the cancer.

Please state previous treatment(s).

Please state current treatment(s)

Child

Please leave the following questions if you do not have a child participating in this study.

How old is your child (years)?

____

What is your child's gender?

Male
Female
Other

Does your child attend any of the following?

School, please indicate what year ______________

Kindy

Childcare

None of the above, my child is solely cared for at home

What primary language does your child speak at home?

English
Other, please specify

____

In which country was your child born?

Australia
Other, please specify

____

Is your child of Aboriginal or Torres Strait Islander origin?

Yes
No

Thank you for taking the time to complete this.

Appendix I

Interview guides

Health Professionals

Number	Question	Prompts
1	Tell me about your contact and involvement with patients' children?	*Experiences*
2	What do children come in for? What do they talk about with you?	*What is life like for these children?* *What is going on for them?*
3	How do you feel patients' children are affected by their parents' cancer?	
4	What do you think would help patients and their children?	
5	What are your concerns for the wellbeing of patients' children?	
6	What supports do you feel children need to adjust to their parent's cancer diagnosis and treatment?	*Are these supports available* *What supports are available?*
7	Are patients' children supported in clinical practice?	
8	How might staff be assisted in providing support for children?	*How would you suggest these children could be better supported and assisted?*
9	Is there anything else you would like to say?	

Parents

Number	Question	Prompts
1	Can you tell me a bit about who is in your family?	*Such as who is in your family? Do you have any pets?*
2	What activities do you and your family enjoy doing together?	
3	Has any of this changed since your/your partner's diagnosis?	
4	Tell me about your cancer diagnosis	
5	What are the key challenges you have faced since your/your partner's diagnosis?	
6	Do you feel okay talking to your children about your/your partner's cancer and any changes?	*[If not]* Okay, why is that? *How have you talked to your children?*
7	How do you think your child/ren has/have been affected by your/your partner's cancer? How do you feel your child/ren has/have coped with your/your partner's cancer diagnosis?	
8	Have you noticed any other changes in your child's/children's behavior?	
9	What, if any, worries or concerns do you have for your child/ren and their coping with your/your partner's cancer?	

10	Do you feel confident and comfortable with supporting and assisting your child/ren to cope with your/your partner’s cancer, and any problems or issues that might arise?	*What support have you had?*
11	Is there anything that might make you feel more comfortable to do this?	
12	What are the main challenges you face with supporting your child(ren)?	*Is there anything else you would like to say?*

Children

Number	Question	Prompts
1	Can you tell me about your family?	Such as who is in your family? Do you have any pets?
2	What are the fun things your family enjoy doing together?	Have any of these things changed lately?
3	Is there anything that you worry about?	
4	I was hoping you could tell me a little bit about your [mum/dad]. Has [mum/dad] been sick lately?	
5	What do you call [mum’s/dad’s] sick/sickness?	
6	Tell me what you know about [mum’s/dad’s] sickness?	
7	If you have a question about [mum’s/dad’s] sickness, who do you ask or what do you do?	
8	Is mum and dad OK talking to you about [mum/dad] not being well?	*[If yes]* Tell me some of the things you talk about with mum and dad? *[If no]* Would you like to be able to talk to mum and dad about this more?
9	Are there more things you want to know about [mum’s/dad’s] sickness?	*[If yes]* Tell me what sort of things?
	What are some things you do to help you feel better about [mum/dad] not being well?	
	Has life been different since [mum/dad] found out [he/she] was not well?	*[If yes]* Tell me how it has been different?
	Are things still the same with your friends, or have they changed?	*[If they have changed]* Tell me how they have changed?
	Are things still the same at school, or have they changed?	*[If they have changed]* Tell me how they have changed?
	Is there someone at school you prefer to talk to about [mum/dad] not being well?	*[If yes]* Tell me who this person is?
	What makes you feel the happiest lately?	[Prompt] Activities? Things? Items? People?
	And, what makes you feel unhappy or sad lately?	[Prompt] Activities? Things? Items? People?
	If I asked you to do a special activity with mum or dad, and it could be any kind of activity, what would that special activity be?	

	If you had a friend that found out their mum or dad was not well in a similar way to your [mum/dad], what would you do to help that friend?	
	If you had 3 wishes, what would those wishes be?	