Parenting while dying:
Hospital-based supportive care of parents with advanced cancer

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Abstract

Every year in Australia thousands of parents raising minor-aged children are dying from cancer. Parenting with incurable end-stage cancer (IESC) gives rise to unique multidimensional stressors that can greatly affect the psychosocial wellbeing of parents and their children. Research shows that parenting concerns are commonly experienced and can impact on healthcare decision-making. Surprisingly, however, parenting-related support needs are not routinely addressed as part of hospital-based healthcare services.

This dissertation contributes the first Australian series of interconnected studies exploring hospital-based interdisciplinary service responses to patients' and co-parents' parenting support needs, offered as part of routine palliative cancer care. A mixed methods exploratory design comprising three sequential linked study phases underpinned the research project.

The first phase entailed data mining the hospital medical records of 74 adult patients diagnosed with IESC (27–75 years, *M* = 47; 61% female; received hospital palliative cancer care between September 2013–December 2015) and parenting minor-aged children. Documented clinical, sociodemographic, psychosocial and hospital-based interdisciplinary parenting support response data were collected and analysed using descriptive statistics. Using qualitative methodologies, the second and third phase studies explored multidisciplinary health professional (HP) and parent perspectives on patient/co-parent parenting supportive care needs and experiences, and factors influencing hospital-based parenting supportive care utilisation and provision. Semi-structured interviews (1 focus group, 2 individual interviews) with 12 multidisciplinary HPs working at an Australian metropolitan general hospital (8 disciplines, *M* = 19.7 years of HP experience) were conducted in August 2017. Following, semi-structured interviews with 12 parents (8 patients, 4 co-parents) were conducted (October–December 2017). Each phase was analysed

individually using thematic analysis. Individual findings from each phase were synthesised to explore overall project findings.

Analysis revealed multidimensional parenting-related support needs were experienced by a diverse sociodemographic cohort of adult patients (aged 27–75 years old; 62% female). Parenthood was largely challenging—insights into the dynamic and unique nature of parenting concerns throughout the IESC phase were provided—from IESC diagnosis to bereavement. Support needs varied in nature and timing across the IESC treatment phase for individual families. The complex psychosocial context within which parenting occurred was indicated by the broad array of pressing psychosocial issues voiced.

A tailored, patient-centred, family-focused, trauma-informed, interdisciplinary approach to hospital-based parenting support was deemed optimal. However, in practice it was not always achievable, resulting in parents experiencing unmet needs. Parents and HPs viewed multisystem factors as influencing parenting support provision and utilisation. Key facilitating factors were hospital-wide systemised parenting practice procedures (e.g., parenting status screening, needs assessments and interventions), adequate clinical resourcing, targeted HP training, collaborative communication, professional supervision and a child-friendly, culturally safe hospital environment. Multidimensional psychosocial factors including emotional and psychological readiness, personality, and beliefs about death and dying impacted on parents' engagement with parenting-related support.

Using these insights, multilevel system approaches for strengthening hospital-based parenting supportive care to parents facing IESC alongside treatment are discussed. Findings together with existing parental cancer research may assist hospital management and interdisciplinary HPs engaged in policy decisions and intervention delivery to develop and implement new initiatives targeting parenting-related psychosocial distress.

***Keywords*:** data mining; health professional; healthcare; hospital; mixed methods; palliative care; parental cancer; parenting; parenting supportive care; psychosocial intervention.

To the parents who so kindly and willingly gave of their precious time to share their experiences. A valuable gift given.

Declaration

This is to certify that:

i The thesis comprises only my original work towards the Doctor of Philosophy except where indicated in the Preface.

ii Due acknowledgement has been made in the text to all material used.

iii The thesis is fewer than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.

Signed: Vera Steiner

Preface

This thesis is the culmination of a three-phased research project in which I was the primary researcher. It was supported by an Australian Government Research Training Program Scholarship.

The thesis contains four papers to which authors contributed. The Contribution of the doctoral candidate on each paper was greater than 50% in accordance with the requirements of The University of Melbourne. Contribution of authors to the published, accepted and submitted papers are included at the start of each of chapter (Chapters 1, 3–5). The publication status of chapters presented in part/full article format:

Journal publications/manuscript articles	Authors	Status
Chapter 1 - Literature Review (part) Psychosocial interventions for parents with incurable end-stage cancer: A rapid evidence assessment	Steiner, V. Shlonsky, A. & Joubert, L.	Published in *Australian Psychologist* in October 2017
Chapter 3 - Phase I study (full) Parenting in the palliative stage: A clinical data-mining study of hospital-based supportive care	Steiner, V, Joubert, L. Shlonsky, A. & Dabscheck. A.	Under review: submitted for publication in *Social Work in Health Care* on 6 August 2019
Chapter 4 – Phase II study (full) Hospital parenting support for adults with incurable end-stage cancer: Multidisciplinary health professional perspectives	Steiner, V. Shlonsky, A. Joubert, L. & Morris, A.	Accepted 30 July 2020: publication in *Health & Social Work*
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Third party copyright material	Location	Permission granted
Steiner, V. Shlonsky, A. & Joubert, L. (2017). Psychosocial interventions for parents with incurable end-stage cancer: A rapid evidence assessment: *Australian Psychologist*, *52*, 381–391. doi:10.1111/ap.12286	p. 28	Yes
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Foremost, my heartfelt appreciation goes to my family and friends who have lived this journey constantly alongside me with much patience, love and encouragement. In particular to my partner Nigel for his unwavering kindness, support and good humour—and for his IT, proof reeding [sic] and barista prowess. To my two sons Mitchell and Jaydon for inspiring me to undertake this PhD research project and taking time along this journey to connect, listen and offer reflections and insights. To my (late) father Alfred whose gentleness and quiet caring nature continues to resound and help ground me. I thank my mother Eva and partner Siegfried (late), my parents-in-law Jan and David and family for their care, support and for enriching my lifelong learning journey. Deep gratitude goes to Chope, Palden (late) and family, Venerable Dupseng Rinpoche and Venerable

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Table of Contents

List of Figures and Tables

CHAPTER 1

Article 1: *Psychosocial interventions for parents with incurable end-stage cancer: A rapid evidence assessment*

CHAPTER 2

CHAPTER 3

Article 2*: Parenting in the palliative stage: A clinical data-mining study of hospital-based supportive care*

CHAPTER 4

***Article 3**: Hospital parenting support for adults with incurable end-stage cancer: Multidisciplinary health professional perspectives*

CHAPTER 5

***Article 4**: Australian hospital-based parenting support for adults with incurable end-stage cancer: Parent perspectives*

CHAPTER 6

CHAPTER 1

Introduction and literature review

Overview

This first chapter of the thesis starts with an insight into the personal and professional experiences that have motivated me to undertake the PhD, followed by a literature review. The chapter then offers a rationale for the thesis and an outline of the project aim and research questions. An overview of the thesis structure and working definitions are provided in the final section.

This chapter contains the original work:

Steiner, V. Shlonsky, A. & Joubert, L. (2017). Psychosocial interventions for parents with incurable end-stage cancer: A rapid evidence assessment. *Australian Psychologist*, *52*, 381–391. doi:10.1111/ap.12286

Author	(%)	Contribution
Vera Steiner	70	Conception and design, analysis and interpretation of data and drafting of manuscript
Aron Shlonsky	15	Concept and design, interpretation of data and critical review of manuscript
Lynette Joubert	15	Concept and design, interpretation of data and critical review of manuscript

A place to stay untouched by death
Does not exist.
It does not exist in space, it does not exist in the ocean,
Nor if you stay in the middle of a mountain.

(Buddha)

A professional and personal perspective

The genesis of this research project emerged while working as a hospital social worker. My psychosocial practice included providing supportive care to patients who were raising young families and receiving noncurative cancer treatment. These families were often highly distressed, with patients grappling with taxing healthcare treatments and everyone hanging onto the hope that their life would be prolonged. For most of these parents, not being able to protect and nurture their children into adulthood was their greatest fear being realised. Witnessing the pain, disbelief, sadness and resilience of these families was deeply moving. I reflected on how as a society we often struggle to speak openly about parenting matters in relation to death and dying—multidisciplinary health professionals included. The topic of prognosis, death and dying is often danced around by practitioners with unclear language being used or discussions altogether being avoided, adding to families' confusion and impacting on their capacity to make informed decisions regarding preparing themselves and their children for the journey ahead. Talking with patients about their parenting concerns when prognosis is poor is understandingly challenging for practitioners, patients and their families.

Through direct practice it became apparent that patients diagnosed with incurable end-stage cancer who are parenting minor-aged children were not routinely offered parenting support as part of their hospital psychosocial supportive care. Different approaches to supporting these families were taken, with some

practitioners waiting for patients to cue them by raising parenting-related questions, such as what they should tell the children about their cancer diagnosis. For some families using this approach resulted in missed opportunities to receive needed psychosocial supportive care that could have helped alleviate distress for the palliative parent in their final stage of life and improve the psychosocial wellbeing of the family into the future. Ultimately, the choice of engaging with parenting supportive care lies with the patient and their family but the responsibility for offering support lies with the multidisciplinary healthcare team.

The clinical context

Incurable end-stage cancer

Cancer is a broad term covering over 100 diverse diseases that can affect any part of the body. Cancer, also known as neoplasm or malignant tumour, arises when abnormal cells in the body grow uncontrolled beyond their usual boundaries. Where the cells have invaded adjoining parts of the body and organs, the cancer has metastasised. Metastatic cancer is described in the literature as advanced, stage-four, end-stage, terminal or palliative-stage cancer (Armstrong, 2015). In this study incurable end-stage cancer (IESC) is defined as any Stage 4 cancer (all cancer types except brain tumours) and any Grade 4 cancer (brain tumours) also known as metastatic cancer where curative treatment was not the aim of care.

Cancer is a primary cause of mortality globally (World Health Organization [WHO], 2018) in countries of all income levels (Torre, Siegel, Ward & Jemal, 2016). In 2018 cancer accounted for approximately 9.6 million deaths worldwide, equating to 1 in 6 deaths (WHO, 2018). The most common cancers causing death are lung (1,760,000), colorectal (862,000), stomach (783,000), liver (782,000) and breast (627,000) (WHO, 2018). Current trends indicate that incidence and mortality from cancer is predicted to rise (Torre et al., 2016) due to factors including population growth, lifestyle choices and aging.

In Australia, cancer was the primary cause of death in 2016 (Australian Institute of Health & Welfare [AIHW], 2019b). For 2019 it is estimated that the leading types of cancer causing mortality will be lung (9,034), colorectal (5,597), prostate (3,306), breast (3,090) and pancreatic cancer (3,051) (AIHW, 2019a). National data has revealed that from the period 1986–1990 to 2011–2015 the five year relative survival rate increased from 50% to 69% for all cancers combined (AIHW, 2019a). In 2018, Australian national cancer stage-at-diagnosis data became available for the first time for the five highest incidence cancers—breast (female), colorectal, lung, melanoma and prostate (Cancer Australia, 2018). The data indicates 77% of initial cancer diagnoses are detected at an early stage; however, diagnoses of some cancers such as lung cancer (42%) often occur when it has progressed to advanced Stage 4 status (AIHW, 2019a). There were comparable staging distribution trends per cancer type across socioeconomic status areas for both sexes (National Cancer Control Indicators, 2018).

Prevalence: parental IESC

Unlike many life-threatening illnesses, cancer causes early impairment and death for parents with minor-aged children (Park et al., 2016). International epidemiological data on the prevalence of advanced parental cancer is sparse (Weaver, Rowland, Alfano & MCNeel, 2010; Zaider, Salley, Terry & Davidovits, 2015) as cancer staging and parenting status data (age of dependent children) is not collected by national Cancer Registries. This is also true for Australia. That said, the possibility of parents living with IESC and caring for dependent children is anticipated to increase due to growing survival rates resulting from improvements in cancer treatment (National Cancer Institute, 2019) and the delay of parenthood until later adulthood (Gotze et al., 2017; Inoue et al., 2015).

Using available national population-based data it is possible to obtain a general indication only—likely an underestimation—of families with children aged [0–18] years old living with IESC. In Australia projected 2019 mortality figures indicate

cancer will cause the death of around 49,896, with 14% (6,985) likely to be younger than 60 years old (AIHW, 2019b) and within parenting age. Interpolating 2016 Australian national Census data that states the average number of children per family unit was 1.8 (Australian Bureau of Statistics, 2017), approximately 12,500 minor children will lose a parent (under 60 years old) to terminal cancer in 2019. International US-based data from 2015 indicates that 338,840 adults died from cancer who were of child-rearing age (20–74 years) (Bray et al., 2018). A previously published population-based US study reported that close to 18% of patients newly diagnosed with any stage of cancer were parenting at least one child aged 18 years or younger, with around 55,000 children estimated to suffer parental loss every year due to cancer (Weaver et al., 2010). In Canada, estimations suggest 17% of cancer mortalities will occur in adults (25–59 years) during their critical child-rearing years (Rainville, Dumont, Siard & Savard, 2012). From this data, it is apparent that palliative-stage cancer influences the lives of a significant number of parents and their children.

Theoretical framework

This section provides an overview of the predominant theoretical perspectives that inform the analytic framework of this thesis—family systems (Hepworth, Rooney & Larsen, 1997), stress and coping (Hutchison 1999a; Mitschke, 2008; Walsh, 1999), life course (Hutchison, 1999b), patient-centred healthcare approach (Coulter & Ellins, 2007) and interdisciplinary collaborative healthcare model (Donaldson, Corrigan & Kohn, 2000). The central concepts of each perspective are discussed in relation to the parental cancer experience and psychosocial hospital service responses to parenting supportive care needs.

Family systems theory

Family systems theory suggests families each operate as a unique system (Hepworth et al., 1997) and there are biopsychosocial factors that can affect the

ideal functioning of a family and cause disorder (Dore, 2008). Every family member is understood to influence one another (Hepworth et al., 1997; Mitschke, 2008). When a parent has life-threatening cancer—a non-normative stressor—ideal functioning is impacted, with members of the whole family affected (Dubois & Miley, 1999; Hepworth et al., 1997), and a family crisis of varied description likely ensues (Elmberger, Bolund & Lützén, 2000; Walsh, 2009). Strong evidence from parental cancer research has identified links between parent and child psychosocial wellbeing—a parent's psychological state impacts on the child's wellbeing and the behaviour and wellbeing of a child affects the parents (Barlow, Smailagic, Huband, Roloff & Bennett, 2014; Helseth & Ulfsaet, 2005; Hymovich, 1993; Niemelä, Repo, Wahlberg, Hakko & Räsänen, 2012; Rauch, 2007; Semple & McCance, 2010). During the various disease stages—crisis, chronic and terminal—individual and family developmental tasks are likely to be disrupted (Rolland, 2005). For instance, the sick adult may be unable to fulfil parenting roles and responsibilities as usual. Optimally, families will have the capacity and resources to respond and adapt to arising normative and non-normative stressors (Sutphin, McDonough & Schrenkel, 2013; Walsh, 2003a, 2006) and re-establish a more functional state known as 'homeostasis' (Hepworth et al., 1997) irrespective of family form, such as single, nuclear, kinship, adoptive and same-sex (Walsh, 2012). However, if some level of reasonable functioning is unable to be re-established, support from outside of the family unit might be required to assist with establishing a new (and evolving) functional normal. Assistance may be in the form of informal supportive care (e.g., via friends) and/or formal support (e.g., parenting support service). Formal and informal social support systems occur across and within systems (Hutchison, 1999a; Payne, 1997; Walsh, 1999) and can offer resources that may help facilitate the restoration of healthier functioning of individuals within the family and family unit. As described by Payne (1997), the family system is not only influenced by the internal interactions between individuals within the family unit but also by factors occurring at the broader

community and societal system level within which the family system resides, including the hospital healthcare system.

The Family Systems Illness model (FSI) developed by Rolland (2005) builds on family systems theory and individual and family developmental theories. It offers a developmental context of cancer comprising three evolving threads: illness, individual and family development. It provides a practical psychosocial strengths-oriented framework for understanding how biological time phases of illness—crisis (e.g., initial period of readjustment and healthcare treatment following diagnosis and prognosis), chronic (e.g., day-to-day living with cancer experienced as constant, progressive or changing episodically) and terminal (e.g., death is inevitable, evident and heavily influences family life)—can interconnect with psychosocial developmental processes leading to distress (Rolland, 2005). The assumptions underpinning this model include that coping with cancer is a dynamic and evolving process that occurs over time, each illness phase has distinct stages comprising particular psychosocial developmental tasks, and the possibility for resilience and growth, aside from risks and detrimental impacts (Rolland, 2005).

For parents and their families facing IESC, various developmental challenges will likely occur during the crisis, chronic and terminal phases. Crisis periods may occur at different junctures along the disease trajectory and prompt family members to develop an understanding of the cancer from a psychosocial perspective, including the emotional, developmental, practical and longitudinal aspects (Rolland, 2005). The chronic phase, whether long or contracted, is proposed as presenting challenges such as balancing family communication (e.g., open vs denial/avoidance) and proactive future planning in parallel to living a 'new normal' life in conjunction with managing anticipatory loss and uncertainty. Such issues are frequently reported in parental cancer research literature as contributing to distress for parents and family members. As the cancer reaches the terminal phase, challenges may include dealing with unresolved family matters, grief,

focusing on quality of life matters and starting the family reorganisation process (Rolland, 2005).

Developing functional collaborative relationships with healthcare providers is another challenge proposed in this model. In the context of parental cancer, clinical experience and research evidence (Inhestern, Haller, Wlodarczyk & Bergelt, 2016) indicate such healthcare-related challenges extend beyond the initial establishment of collaborative relationships. Relationships are likely to require development and renegotiation along the cancer journey as different healthcare teams become involved at different junctures and inpatient/outpatient settings. For instance, a hospital multidisciplinary neurosurgical team may provide parenting supportive care for a short period while surgical treatment is received (e.g., parent with a brain tumour undergoes resection surgery) before the responsibility of care is transferred to another healthcare team (e.g., oncology or acute rehabilitation service) prior to hospital discharge. These systems-related challenges highlight not only the difficult tasks dying parents and their co-parents are often encumbered with but importantly, the responsibility individual HPs and healthcare teams have in facilitating collaborative communication across the crisis, chronic and terminal phases to reduce parent distress.

Stress and coping theories

Stress and coping theories are interconnected. Employing ineffective coping strategies can increase experiences of stress and consequently impact on a person's physical and psychological health and social functioning (Lazarus, 2000). Coping is a multidimensional process that requires effort to adapt to circumstances that have been appraised as stressful (e.g., a terminal cancer diagnosis) (Lazarus & Folkman, 1984) and these efforts can mediate the outcome of a distressing situation (e.g., level of anxiety or distress) (Lazarus, 1993). What is appraised by an individual as stressful will vary from person to person and their ways for dealing with stress will also depend on their internal and external resources. Some stress-

inducing situations are considered normal and are anticipated as part of normal family processes (Dore, 2008) while other stressors will test even families that are highly functioning. This thesis draws on the social work standpoint of coping, whereby human behaviour is viewed from a bio-psycho-social-spiritual perspective based on systems and the reciprocal relationship between persons and their environments (Walsh, 1999).

Parenting minor-aged children can induce higher levels of distress in adults compared to persons who have adult children or are childless (Umberson, Pudrovska & Reczek, 2010). Nomaguchi and Milkie (2003) describe parenthood as a transformative experience—causing an array of stressors and rewards—that impact on parents physically, psychologically and socially. From this standpoint, parents with minor-aged children who face a contracted future will likely experience an array of normative (e.g., financial issues) and non-normative (e.g., early unexpected death) psychosocial stressors, as well as benefits. Published advanced parental cancer research studies provide numerous descriptions from parents', children's and health professionals' perspectives of parenting-related stressors incurred and coping responses (Aamotsmo & Bugge, 2014; Visser et al., 2007; Krattenmacher et al., 2012)—viewpoints that help to broaden understandings of the multidimensional psychosocial impact of parental cancer on the ill parent, co-parent, children as well as family functioning.

There is variability with how parenting-related concerns are appraised by parents, their stress responses and ways of coping. Lazarus (1993) and Lazarus and Folkman (1984) propose two general categories of coping styles—problem-focused and emotional-focused—that are founded on a person's goals or intentions. In the case of palliative-stage parental cancer, parents may focus efforts on changing an aspect of the stressor (e.g., unsure how to tell children about their terminal diagnosis) using problem-focused coping (e.g., seeking developmentally appropriate information on how to talk with their children from their treating healthcare team) and deal with the distressing emotions that arise in a stressful situation through

emotional-focused coping (e.g., managing their anxiety). Examination of the parent- and family-based psychosocial intervention research literature reveals a large focus on supporting and guiding parents (and children) to manage the myriad of practical and emotional challenges by assisting parents and families enhance their "coping skills and sources of resilience" (Stone, Berzin, Taylor & Austin, 2008, p.31) through strategies such as counselling, psychoeducation, guidance, resourcing, advocacy and linkage with support services (Bugge, Helseth & Darbyshire, 2008, 2009; Kühne et al., 2012).

Life course theory

The developmental wellbeing of an adult with life-threatening cancer is not only influenced by their experiences of the cancer but the psychosocial context—including timing—within which it occurs. Premature death is largely unexpected yet commonly feared among parents raising young families. Serious parental illness and death are two of the most stressful life events for minor-aged children (Howell et al., 2016). Strong societal beliefs suggest that it is not expected for parents to outlive their children (De Vries, Dalla Lana & Falck, 1994) however the death of a parent who is raising minor-aged children prior to late adulthood challenges the perceived natural order of the universe (Saunders, 1979–1980) and also opposes common notions of health and survival in current Western cultures (Exley & Letherby, 2001; Hilton, Emslie, Hunt, Chapple & Ziebland, 2009).

From the perspective of life course theory (Elder, 1995; Hutchison, 1999a), it is assumed that the life of each individual has its own unique trajectory—marked by a long-term pattern of stability and change—and influenced by person- and environmental-based factors over time (person-in-environment). It provides a framework that can help understand individual behaviour—the social context, timing (i.e., historical), age and relationships (i.e., marital, child-parent) within which people exist and interact. Recognition is given to social, cultural and historical contexts with "life course markers" (Hutchison, 1999a, p.23) being widely

shared across particular cohorts and cultures and the influence of unanticipated life events (e.g., terminal parental cancer diagnosis) is acknowledged. For example, parenthood in developed countries is now occurring later in the life course than was commonplace several decades ago (Gotze et al., 2017; Inoue et al., 2015). Life course theory views individuals' lives as entailing the transitioning through various roles and statuses that are markedly different from prior ones. Further theoretical principles include human agency and self-regulation (e.g., choices individuals make regarding life events such as death, dying and healthcare decisions) and humans' interdependent relationships (e.g., parent-children) (Stone et al., 2008). Stone et al. (2008) bring attention to the reconceptualisations of the life course framework developed by Elder (1995). Rogoff (2003) offers a repositioning of culture as central and embedded in the human development process; life transitions are viewed as heavily influenced by culture—cultural traditions, institutions, family life and community practices. Culture is considered as ever changing and redefined by time and place, as are individuals; individuals' behaviour has a reciprocal relationship with cultural processes. Hunt (2005) contributes the importance of taking into consideration the influence of institutions and processes on human behaviour which has resulted in increases to the human life span and changing age-related transitions—technology, economics, culture and politics. Therefore, from a life course perspective, the "turning point" (Hutchison, 2005, p.145) of early death in adulthood, parental role, psychosocial factors and healthcare supportive care services are linked.

Patient-centred healthcare approach

Quality patient-centred healthcare is based on the principles of patient engagement, informed decision-making and consumer preferences (Coulter & Ellins, 2006). Models of patient-centred care have been developed to encourage patient engagement in health care including decision-making, enhancing patient satisfaction and achieving improved treatment and health outcomes (Coulter & Ellins, 2007; Greenfield, Kaplan & Ware, 1985). Compassionate and responsive

approaches to patient-centred healthcare take into full consideration patients' needs, values and choices (Australian Commission on Safety and Quality in Health Care, 2011; Berwick, 2009; Dwamena et al., 2012), affirming a commitment to recognising patients' humanity (Frampton, Guastello & Lepore, 2013; Zulueta, 2013) and ensuring care provided is evidence-informed (Kvåle & Bondevik, 2008). Internationally, a patient-centred healthcare approach is considered to be the optimum model of practice (Dwamena et al., 2012; IOM (2011). In Australia, it underpins cancer and palliative psychosocial care policies, frameworks and standards (Department of Health and Human Services Victoria, 2018; Palliative Care Australia, 2018, Turner, 2015), and clinical practice guidelines (Grassi, Spiegel & Riba, 2017; National Breast Cancer Centre [NBCC] & National Cancer Control Initiative [NCCI], 2003). The approach is also considered central to hospital-based psychosocial supportive care targeting families facing cancer (Loscalzo, Clark & Bultz, 2015) as well as services specifically providing parenting support to patients and co-parents facing end-stage cancer (Bugge, Helseth & Darbyshire, 2008, 2009; Swick & Rauch, 2006).

In keeping with the principles of a patient-centred approach to healthcare practice, this practice-based research project was designed to include the important viewpoints of patients (and co-parents) facing palliative-stage cancer. A key component of exploring, understanding and meeting the existing and future needs of patients and their families and to outwardly value their humanity is to provide them with safe and supported opportunities to voice their lived experiences, parenting support preferences and needs—met and unmet—as well as ideas for improving care (Jubb, 2002; Sandsdalen, Hov, Høye, Rystedt & Wilde-Larsson).

Interdisciplinary collaborative healthcare model

Collaborative interdisciplinary care is a primary factor for influencing the quality and safety of healthcare delivery and improving patient outcomes and health (Donaldson, Corrigan & Kohn, 2000), and is recognised as an essential component

of patient-centred care (Jessup, 2007). Collaborative interdisciplinary care is defined as a team of clinicians from different health profession disciplines working in partnership with patients to complete assessments, undertake diagnoses, develop healthcare goals and care plans, involve patients and their families/carers in discussions about their condition, prognosis and care plan, and facilitate service improvement (Jessup, 2007; Loscalzo, Clark & Bultz, 2015). Over the past twenty years, interdisciplinary models of care have featured as a component of quality patient- and family-centred psychosocial oncology and palliative care in Australia (DHV, 2002; Department of Human Services, 2008; DHV, 2011; DHV, 2019a) and internationally (Bultz, 2016; Thiel, Harden, Brazier, Marks & Smith, 2019; Loscalzo, Clark & Bultz, 2015).

Psychosocial supportive care in present hospital systems is viewed (in optimal circumstances) to be collaborative in nature (Loscalzo, Clark & Bultz, 2015). Efficacy studies examining healthcare team interventions have increased significantly over the past decade to determine how collaborative processes and practices can be enhanced. A recent systematic literature review (Buljac-Samardzic, Doekhie, & van Wijngaarden, 2020) identified four categories of team interventions that occur in large healthcare institutions (predominantly hospitals) to improve team performance outcomes. They comprised: a) training; b) tools that organise (e.g., assessment forms, [de]briefing checklists and structured interdisciplinary meeting around the patient), facilitate (e.g., communication technology) and prompt (e.g., monitoring and feedback) teamwork; c) organisational (re)design (e.g., team processes and functioning including clinical pathways and staff roles and responsibilities); and d) programs.(e.g., tailored combinations of different interventions that take into account individual organisational contexts). Strong empirical evidence found that training, programs and (de)briefing checklist tools were effective approaches for enhancing healthcare teamwork. Further high-quality studies focusing on organisational (re)design and tools are needed to clarify their effects on enhancing teamwork and patient health and treatment outcomes (Buljac-Samardzic, Doekhie, & van Wijngaarden, 2020).

Research exploring the interdisciplinary approach to hospital-based parenting supportive care for adult patients with IESC (and their co-parents) has received limited attention. To date, intervention studies appear to have largely focused on medical and nursing practice (Dilworth et al., 2014; Turner et al., 2007b) at the exclusion of other healthcare team members who may play an essential role (for instance, social work). As such, a wider interdisciplinary perspective covering the types of parenting supportive care practices that occur in hospitals, and the factors that hinder and facilitate optimal care provision, require further exploration.

Parent and family experiences of IESC

Parenthood

For many adults, parenting is a primary role and a major concern when diagnosed with cancer (Stinesen-Kollberg et al., 2013); the experience of parenting significantly alters when faced with a poor prognosis. Receiving a life-threatening diagnosis can be a traumatic experience (Lawson & Lawson, 2018), activate previous trauma (Altschuler & Dale, 1999) and potentially overwhelm parents' capacity to cope with simultaneously managing illness-related and parenting-related demands (Park, Check et al., 2017). Current research (including parents raising children up to 18 years old but receiving active treatment for metastatic cancer) revealed that parenting efficacy scores for both parents and co-parents were significantly reduced following a cancer diagnosis (Moore, Rauch, Baer, Pirl & Muriel, 2015). Suggested reasons are attributed to parents' concern of the detrimental impact the illness symptoms and changed parenting routines would have on the children's emotional and psychological wellbeing; not protecting the children from the changes was perceived as not meeting their needs (Moore et al., 2015). Overall, parents primarily desire to protect their children.

The contracted disease course generates a multitude of psychosocial challenges. While the strengths and resiliency discourse in the field of parental cancer

continues to grow (Kühne et al., 2013), evidence shows parents with metastatic cancer can struggle with specific parenting challenges that arise during the IESC phase (Hailey et al., 2018; Park et al., 2016). Unlike parents with early stage cancer, they face the hard reality of impending death and all the existential issues that such a diagnosis encompasses in conjunction with managing deteriorating physical symptoms and a myriad of challenging psychosocial tasks—including parenting (Zaider et al., 2015). These parental challenges include worrying what the impact of their illness, prognosis and death will have on their children (Bell & Ristovski-Slijepcevic, 2011; Park, Check et al., 2017; Park, Stephenson, Moore, Deal & Muriel, 2019); when, how and what to discuss with their children about cancer and death (Hailey et al., 2018); dealing with urges to engage in 'accelerated' or 'cram' parenting (Bell et al., 2011; Zaider et al., 2015); creating memories and future planning for their children (Bugge et al., 2009; Nadimi & Currow, 2008; Russell & Rauch, 2012b); helping to maintain family functioning (Bugge et al., 2009) and a sense of 'normalcy' (Zaider et al., 2015); and, facilitating and coping with changing childrearing responsibilities (Bugge et al., 2009). Other responsibilities include attending to financial (Rainville et al., 2012) and legal stressors (Nadimi et al., 2008) and negotiating crucial medical and end-of-life decisions (Nilsson et al., 2009; Russell et al., 2012b)—all while optimising time spent together with loved ones (Elmberger, Bolund & Lützén, 2002; Zaider et al., 2015). These factors can place parents with IESC, co-parents and their children in a uniquely vulnerable position.

Recent gender-based research conducted with patients facing metastatic cancer indicated that parenting-related issues were a source of distress for both fathers (Ernst et al., 2013) and mothers (Bell et al., 2011). Single parents are often distraught from the moment of their cancer diagnosis about how they will manage alone and how their children will be cared for after they die (Behar & Lewis, 2015; Nadimi et al., 2008). Common events such as being hospitalised and extended healthcare-related expenses and childcare expenses can be particularly difficult for parents with limited external supports (Behar et al., 2015). Preparing for their own

death can be overwhelming and while planning for their children's long term future is crucial for parents' sense of control and the stability of the child (Nadimi et al., 2008) yet parents may neglect to adequately prepare for their children's future for various reasons including denial and avoidance or putting their efforts towards a cure (Nadimi et al., 2008; Willis, Peck, Sells & Rodabaugh, 2001). Studies have also shown that parents are not always cognisant of when their children are distressed (Welch, Wadsworth & Compas, 1996) and may benefit from health professional guidance in obtaining a better understanding of what signs to look for and how to communicate with their children (Hailey et al., 2018).

The full dimension of the experiences of parenthood during IESC has yet to be comprehensively explored and understood. Historically, parental cancer research has largely centred on mothers' experiences of cancer (O'Neill, McCaugan, Semple & Ryan, 2018). The perspective of underrepresented patient subgroups such as fathers, parents from culturally and linguistically diverse (CALD) backgrounds (Davey, Kissil, Lynch, Harmon & Hodgson, 2013), those experiencing a low socioeconomic status (Mitschke, 2008; Stikkelbroek, Bodden, Reitz, Vollebergh & van Baar, 2016), single parents (Elmberger et al., 2000; Nadimi et al., 2008), same-sex parents and other under-researched patient subgroups (Mitschke, 2008) are largely absent from the literature and require future investigation as understanding patients' parenting concerns is critically important to patient-centred oncology and palliative care.

Psychosocial impact on parents with IESC

Parents diagnosed with cancer who are parenting young families represent a patient group at high risk of psychosocial distress and suffering (Cancer Australia, 2014; Hailey et al., 2018; National Breast Cancer Centre [NBCC] & National Cancer Control Initiative [NCCI], 2003). Anxiety and depression occur at higher levels in parents diagnosed with cancer who are raising minor-aged children than the general population (Götze et al, 2017). This can reduce their psychological

availability and affect consistency of discipline with parenting (Semple & McCaughan, 2013). Inhestern et al. (2016) found strong associations between emotional distress and parenting concerns with parents with fewer parenting concerns identified as having higher parenting confidence (Inhestern et al., 2016). Studies specifically focused on parents with metastatic cancer raising children aged up to 18 years old have higher rates of anxiety than those without dependent children (Bell et al., 2011; Nilsson et al., 2009). A recent study (Park et al., 2019) found parenting-related concerns might be more strongly linked to generalised psychosocial distress for parents with metastatic cancer than those with early stage cancer. Findings revealed cancer stage did not independently determine the level or range of parenting concerns; the authors suggest the seriousness of parenting concern needs to be considered in context with other clinical, demographic and psychological factors. All findings highlight the potential benefit of promoting parenting confidence through skills and knowledge development.

Anticipatory grief can also impact on parents' emotional status and how they interact and parent their children. Parents have reported enormous guilt for not being there for their children in the future (Thastum, Munch-Hansen, Wiell & Romer, 2006) and sadness at the thought of leaving their children behind (Turner et al., 2007a). For some, such experiences have served as the impetus to shift their focus and priorities to engage more actively in direct parenting activities (such as, spending more time with their children) (Elmberger et al. 2002; Fitch, Bunston & Elliot, 1999) for others the parenting experience has been described as laboured and inauthentic (Bell et al., 2011).

Illness-related parent-child communication is a highly reported concern of parents facing IESC in the research literature. A recent mixed methods study by Hailey et al. (2018) revealed that parent-child illness communication (including prognosis and death) was related to parents' overall higher anxiety. Reasons provided for finding included that parents who shared prognosis news may have acknowledged the likelihood of their own death for the first time whereas parents who did not

discuss the prognosis may not have considered that death was near or likely. It is widely reported that parents are often fearful of traumatising their children by unskilfully telling them about their incurable disease (Bugge et al., 2009; Houldin & Lewis, 2006; Park, Deal, Yopp, Edwards, Wilson et al., 2017; Turner et al., 2007a), feeling unsure how best to act protectively and honestly when discussing the uncertain nature of their cancer diagnosis (Kennedy & Lloyd-Williams, 2009). Talking to children about a parents' imminent death is a difficult topic often avoided but one of great importance; as are discussions with co-parents about how to best support children's coping during the bereavement period (Park, Deal, Yopp, Edwards, Stephenson et al., 2017). Knowing how to initiate and facilitate ongoing prognosis and illness discussions with their children is known to be a particular source of distress for some parents (Hailey et al., 2018). It comes at a time when parents themselves are endeavouring to adapt to the reality of their foreshortened future (Beale, Sivesind & Bruera, 2004).

Parents are reported to worry about co-parents' capacity to care for them and their children during end-stage cancer. A study by Moore et al. (2015) found these concerns surfaced when parents perceived co-parents' efficacy had declined. Similarly in a study involving bereaved fathers, Park, Deal, Yopp, Edwards, Wilson et al. (2017) found that terminally ill wives had expressed their concerns of the strain end-of-life would have on them and the children. Further studies exploring the perspectives of dying fathers are required to determine if such concerns are common experiences for both male and female palliative parents.

Being a parent of a young family can also impact on parents' wellbeing, care and treatment decisions during the latter phase of life. Research has shown that parenting status influences parents' cancer treatment choices (Check et al., 2017; Nilsson et al., 2009), end-of-life care decision-making and planning for their approaching death; and that parents compared to non-parents experience poorer quality of life in the week before death (Nilsson et al., 2009). In the study by Nilsson et al (2009), parents opted for treatment on extending life, not on

alleviating symptoms. More recently a study confirmed that treatment preferences are influenced by parents' desire to prolong time with their children as well as preserve parental functioning and maintain physical proximity to their children (Check et al., 2017). Patients' parental identity is therefore indicated to be of significant relevance to oncology and palliative healthcare.

Psychosocial impact on co-parents

Co-parents in these families can face complex issues as individuals, co-parent in partnership, and as a family member. The multifaceted roles and responsibilities involved with being a primary caregiver to a terminally ill parent and a young family has been described as both distressing (Yopp, Park, Edwards, Deal & Rosenstein, 2015) and rewarding. Anxiety and depression has been identified to occur at higher levels in co-parents of patients diagnosed with cancer than found in the general population (Götze et al., 2017). Co-parents of terminally ill partners have a greater likelihood than nonparents to experience major depression and generalised anxiety symptoms (Nilsson et al., 2009; Yopp et al., 2015).

A review of the research literature (Aamotsmo et al., 2014) shows that during the end-stage of cancer, co-parents described life as being unpredictable and distressing—they found themselves in new roles without a guide, endeavouring to keep life normal and secure, feeling alone contemplating difficult thoughts about the future, needing information and help with supporting the children and putting aside their own needs. Meeting the challenging demands of coping with their own emotions such as grief, fear and anger (often concealed to family members) while adopting new and expanded parenting roles along with being a carer, was often overwhelming (Thastum, Johansen, Gubba, Olesen & Romer, 2008). Emotional and practical issues were viewed as equally challenging (Aamotsmo et al., 2014). It is understood that while some co-parents have the necessary skills, confidence, resources and capacity to manage their own and their children's needs, others may not (Thastum et al., 2008; Semple et al., 2013).

Communication between parents regarding parenting-related issues can be a source of distress for co-parents. A qualitative study interviewing male and female co-parents (MacPherson, 2005) found that co-parents can struggle with the dilemma of establishing consensus within the co-parenting relationship regarding parenting decision-making— whether, how and when to prepare their children for the inevitability of the parent's death. Factors influencing decision-making were the ill parent's wishes, needs and behaviours, the needs of the children and the co-parent's own acceptance of the impending death, ability to balance their own often conflicting thoughts and emotions while partaking in multifaceted responsibilities and their observations of the experiences of death in others. Following the needs and wishes of the parent, whether shared openly or covertly, was usually the path taken even if they did not concord with the surviving parents' preferences.

A recent study comprising 344 widowed fathers identified parenting-related challenges experienced through inadequate communication between parents, and the dying parent and the children (Park, Deal, Yopp, Edwards, Wilson et al., 2017). Findings indicated 50% of mothers did not say goodbye to the co-parent before their death and 38% did not say 'goodbye' to their children; 26% were perceived by co-parents as not being at peace with dying due to worries about the family (Park, Deal, Yopp, Edwards, Wilson et al., 2017). To address these and related concerns, the fathers identified several communication priorities that need to occur between parents facing terminal parental cancer which included talking about the dying parent's preferences for how the children should be raised, how they want to be remembered and discussing how to talk with the children about the parent's approaching death and afterwards (Park, Deal, Yopp, Edwards, Stephenson et al., 2017). The duration of the mother's metastatic illness was found to have no relationship to the stated priorities. Data from this study and previous research point to communication difficulties experienced by co-parents and the importance of earlier prognostic communication from physicians (Park et al., 2015). It is suggested that pre-death discussions including future-based parenting issues could help decrease co-parents' psychological distress during the

bereavement period (Park, Deal, Yopp, Edwards, Stephenson et al., 2017). The importance of offering supportive care to co-parents navigating such challenges during the IESC phase and into bereavement cannot be overstated.

Psychosocial impact on children

Having a parent with cancer places children at risk of distress and developmental disruption (Alexander, O'Connor, Rees & Halkett, 2019). Lewis (2007) argues the experience of parental cancer is a non-normative transition, not a pathological process. Parental cancer impacts on children's overall coping and wellbeing and can trigger various maladaptive psychosocial, emotional and behavioural stress reactions (Visser et al., 2007; Krattenmacher et al., 2012). Research indicates that distress for children and adolescents whose parent has terminal cancer can be higher during the palliative-stage than the bereavement period (Welch et al., 1996; Siegel, Karus & Raveis, 1996). For children of single parents, the palliative stage is often a time of marked instability, particularly if the parent is in denial of their clinical status or the proximity of their death (Nadimi et al., 2008).

A review of the research examining the psychosocial impact of end-stage cancer according to children's developmental stage found that adolescents at more psychological risk during this period than any other age group (Phillips, 2014). Findings by Rainville et al. (2012) revealed adolescents experienced elevated levels of distress and depression compared to the general population. They experienced a disrupted family life, marked by changing roles within the family, including increased responsibilities (Phillips & Lewis, 2015). Adolescents were distressed about the impact of cancer on both themselves and the parent. Worries spanned the past, present and future and included parents' present health status, deteriorating physical function, uncertainty of the immediate future and the parents' death (Phillips et al., 2015). They have different viewpoints on what they wanted from family communication about the cancer (Turner, 2017)—their interest in having open discussions was influenced by the duration of the cancer,

child's age and perceptions of whether it was an unavoidable conversation that needed to be had (Phillips et al., 2015). Overall, communication and information are of particular importance (Krauel et al., 2012) however they are not routinely addressed (Walczak, McDonald, Patterson, Dobinson & Allison, 2018). Factors such as distrust in the healthcare provided to the ill parent has also been shown to increase adolescents' risk of depressive symptoms, with those who were not given end-of-life healthcare information prior to their parent's death were exposed to even greater risk (Bylund-Grenklo et al., 2013). Unmet needs for support also expose adolescents to increased distress (McDonald et al., 2016). Few studies, however, have reviewed the impact of terminal parental cancer specifically on young children. One study conducted with primary school-aged children whose parents had various staged cancers found younger children experienced higher internalising and externalising problems (Visser et al., 2006). What is understood is that children's reactions to parental cancer differ with age, with younger ones having difficulty understanding that their responses are linked to their parent's illness (Bugge et al., 2008). As such, child-centred supportive care guided by the developmental stage of the child is considered best practice (Russell & Rauch, 2012a; Swick & Rauch, 2006).

Strong evidence suggests parent's psychosocial wellbeing is singly an important predictor of a child's wellbeing (Helseth et al., 2005; Hymovich, 1993; Niemelä et al., 2012; Semple & McCance, 2010) and it influences parent-child relationships (Barlow, Smailagic, Huband, Roloff & Bennett, 2014) and that parents are affected by their children's behaviour and wellbeing (Barlow et al., 2014; Helseth & Ulfsaet, 2005; Rauch, 2007). Having parents who are experiencing emotional problems such as anxiety and marital distress can contribute to a child's challenge of adapting to a parent's illness (Huizinga et al., 2011). Poor quality parent-child communication during the terminal phase of parental cancer can contribute to children's feelings of confusion and anxiety (Kennedy et al., 2009). Children who are informed about their parent's terminal diagnosis anxiety levels have been shown to be lower than those children who had not been informed (Rosenheim &

Reicher, 1985). Open, honest and developmentally appropriate communication with children—particularly when a parent is palliative—is widely agreed to be conducive to the welfare of children (Bugge et al., 2008; Semple et al., 2013; Russell et al., 2012a). Poor family functioning proving to be a significant factor relating to increased levels of distress and unmet needs in children (McDonald et al., 2016).

While research has largely focused on the distress-related impact terminal parental cancer has on children, several studies have centred on resilience and post traumatic growth in children (Osborn, 2007; Visser et al., 2007; Kissil, Niño, Jacobs, Davey & Tubbs, 2010; Phillips et al., 2015; Wong, Cavanaugh, MacLeamy, Sojourner-Nelson & Koopman, 2009). Adolescents have reported the experience helped shape their self-image, promote maturity such as fostering independence, and enhanced their life views (Phillips et al., 2015). Another study revealed how children demonstrated significant thoughtfulness and empathy for both their ill and healthy parent's emotional state during this period (Thastum et al., 2008). Protective factors that mediate children's coping, such as communication, parental support, knowledge and understanding of the situation can help prevent psychosocial problems (Bugge et al., 2008).

Impact on family functioning

There is growing recognition of the psychosocial distress that a terminal cancer diagnosis places on the family unit (Edwards & Clarke, 2004; Zaider et al., 2015). From a systems perspective, disruptions occur across all dimensions of family life when a parent receives a poor cancer prognosis (Zaider et al., 2015). Increased family dysfunction in terms of general family functioning and problem solving can occur (Kühne et al., 2013). Terminal parental cancer can greatly increase psychological distress for family members including the children and the co-parent (Phillips, 2014), with psychological distress being experienced interdependently among family members (Schuler et al., 2014). Many families are resilient and have the ability to adapt well to their change in life circumstances (Elmberger et al.,

2002; Helseth et al., 2005; Kühne et al., 2013; Phillips et al., 2015; Wong et al., 2009). Evidence supports that interpersonal family processes—such as the quality of communication, cohesiveness, and conflict management—are highly foretelling of the psychological adjustment of each family member during the palliative phase and post death (Schuler et al., 2014). Buchbinder, Longhofer and McCue (2009) argues adopting a strengths-based approach and concentrating on changes that are occurring in the family—as opposed to a pathological view focusing on psychosocial dysfunction—may assist health professionals to undertake proactive preventive work with families instead of taking a reactive approach to improving family functioning. Identifying families' psychosocial and parenting supportive care needs and facilitating their connection with respective support services is central to optimal palliative and cancer care.

Service response

Policy into practice

Unlike sudden death through acute trauma, a period of forewarning comes with a terminal cancer diagnosis, presenting an opportunity for important parenting concerns to be addressed through psychosocial supportive care (Park, Deal, Yopp, Edwards, Stephenson et al., 2017). Psychosocial supportive care, in the broad sense, is the provision of care that falls outside of the biomedical therapy domain (Fann, Ell & Sharpe, 2012). It focuses on addressing the psychosocial needs of patients to aid in minimising distress and improve quality of life through supportive care (Hoon, Chi Sally & Hong-Gu, 2013)—parenting support being a component of this.

Over the past 15 years significant progress internationally has resulted in psychosocial care being endorsed as an essential element of effective and comprehensive cancer and palliative care (IOM, 2008). In 2009 the International Psycho-Oncology Society (IPOS) successfully advocated for quality care to incorporate the psychosocial concerns of cancer patients and progressed the

international endorsement of distress as the "6th vital sign" (Ristevski, Breen & Regan, 2011), promoting the integration of psychosocial care into routine cancer care, the adoption of distress screening and the provision of evidence-based psychosocial services (Holland, Watson & Dunn, 2011). The UK National Institute of Health and Clinical Excellence (NICE) guidelines incorporated psychosocial care as a means for improving supportive and palliative care (NICE, 2004). The European Union encouraged member states to improve the quality of life of patients by addressing their psychosocial issues along their healthcare journey, and the WHO) established palliative care interventions with the core principle of relieving suffering (Mateo-Ortega et al., 2018). In Australia, psychosocial care has been widely accepted and firmly embedded in the cancer and palliative healthcare agenda by way of healthcare policies (Australian Government Department of Health, 2019; Department of Health Victoria [DHV], 2011), practice standards and frameworks (AIHW, 2019c; Cancer Australia, 2013; Cancer Council Australia, 2011; Palliative Care Australia, 2019), psychosocial clinical practical guidelines (Cancer Australia, 2014; NBCC & NCCI, 2003; Turner, 2015), psychosocial screening tools (Ristevski et al., 2011) and psychosocial care referral checklists (Cancer Australia, 2008).

Despite the significant advancements made to holistic healthcare practice, psychosocial supportive care is yet to be fully implemented into routine healthcare (Dencker, Rix, Bøge & Tjornhoj-Thomsen, 2017; Ristevski et al., 2011; Zebrack, Burg & Vaitones, 2012). Evidence has shown that parents facing IESC cancer do not have their parenting-related support needs routinely met by healthcare professionals (Fearnley & Boland, 2017; Turner et al., 2008). One known exception occurs in Norway; changes to the Norwegian Health Personnel Law in 2010 has mandated that all adults diagnosed with cancer are screened to determine their parental status, and the needs of the children are assessed and child-centred interventions provided as required (Lovdata, 2010 as cited in Aamotsmo et al., 2014; Norwegian Department of Health 2008-2009 as cited in Syse, Aas & Loge, 2012; Semple et al., 2010). This strategy has integrated psychosocial care firmly into routine hospital

healthcare practice. No such legislature is present in Australia; as such, the challenges of translating policy into practice lie with policy makers, organisations and health professionals to collaboratively find feasible pathways forward. Further research on how current policies, standards and practice guidelines promoting holistic patient-centred family-focused supportive care can be implemented to realise optimal parenting supportive care in practice could prove beneficial. Government-based Initiatives targeting the improvement of parenting supportive care practice in healthcare settings, such as the current DHV (2019b) initiative of improving supportive care practice in Victoria is another systemic approach that could be useful for addressing current service shortfalls.

Oncology and palliative psychosocial practice approaches

With the growing body of research, there is now a strong evidence base demonstrating the benefits of psychosocial care in cancer care (Bultz, 2016). Providing psychosocial supportive care to patients with terminal cancer requires health professionals to draw on both the oncology and palliative care principles of quality care. Oncology and palliative care share the common goals of preventing and relieving the distress and suffering of patients and their families with a focus on providing comprehensive care to the whole person (Altilio & Sumser, 2015) utilising a patient-centred, compassionate and strengths-based approach (Palliative Care Australia, 2019).

Current models of psychosocial oncology care focus on easing distress, viewing it as an expected and normal response when patients experience a life-limiting illness (Mateo-Ortega et al., 2018). Distress is defined as a "multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural and emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer" (National Comprehensive Cancer Network, 2020, p.6). Optimal supportive care is understood as being offered from the point of diagnosis through to bereavement care (Waldrop & Weisenfluh, 2015). Palliative care aims to improve

"the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2016, para. 1). The psychosocial care of the patient occurs across a continuum, not as a one-off intervention (Australian Government Department of Health, 2010). Care is premised on developing a relationship with patients and is a process, based on not just a brief one-off intervention—but a series of small, intimate discussions that facilitate rapport building and establishment of trust (Gerbino, 2014).

Psychosocial interventions for parents with incurable end-stage cancer: A rapid evidence assessment

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Abstract

Objective: Parenting is a primary concern for patients with minor children facing palliative-stage cancer, yet psychosocial support addressing parenting concerns during end-stage cancer is not routinely provided in the healthcare setting. The purpose of this review is to: (a) identify evaluation studies describing psychosocial interventions for parents with incurable end-stage cancer; and (b) review the effectiveness evidence.

Method: This review was based on a rapid evidence assessment using transparent and comprehensive search terms and narrative synthesis. Inclusion criteria were broad and consisted of qualitative, quantitative, and mixed method studies that focused on psychosocial interventions for parents with advanced cancer.

Results: Four studies were identified, but only one of these reported results specific to parents with end-stage cancer. A child-centred and family-focused approach was central to all program interventions. All programs encompassed a structured format with the majority being dedicated to providing both individual and family sessions. The studies varied in methodological quality and all used

small, nonrepresentative samples limiting the generalisability of the findings. There were no high quality quantitative studies that specifically address outcomes for this parent group and few qualitative studies that detail parents' intervention experience.

Conclusions: The findings suggest that targeted, child-centred, family-focused psychosocial interventions are sometimes used to support adult patients with parenting during end-stage cancer. These purport to promote child-parent communication and to contribute to parent psychosocial wellbeing. Further research using larger parent populations from diverse sociodemographic backgrounds is required. More importantly, comparative effectiveness studies are needed that test the timing, delivery, and content of these interventions.

Key words: advanced cancer; palliative care; parental cancer; parenting; psychosocial intervention

What is already known on this topic:

1. Patients facing incurable end-stage cancer who are parenting minor children frequently have complex needs, are at high risk of psychosocial distress, and are often deeply concerned about how to manage parenthood during this time.

2. Parents with incurable end-stage cancer frequently fail to have their psychosocial supportive care needs addressed in the healthcare setting.

3. There is a scarcity of parenting-focused psychosocial intervention research within cancer care and palliative care

What this paper adds:

1. All psychosocial interventions identified in this review shared the characteristics of being structured and time-limited programs that were child-centred and family-focused.

2. Published psychosocial intervention efficacy studies targeting parents with incurable end-stage cancer are scarce and contain small samples, and caution is required when making recommendation for clinical practice; nonetheless, these limited findings suggest that family-focused approaches can potentially provide beneficial psychosocial outcomes.

3. Further intervention research using larger parent populations from diverse socio-demographic backgrounds is required to assess whether such interventions result in improved parenting and better parental psychosocial functioning. Importantly, comparative effectiveness studies are needed that test the timing, delivery, and content of these interventions.

Introduction

Cancer is one of the leading causes of death worldwide (World Health Organisation, 2015). In Australia, national data on parental cancer is not collected, however it is likely that thousands of parents with dependent children in Australia are living with advanced cancer, given 45,780 of adults were estimated to die from cancer in 2014 (Australian Institute of Health and Welfare, 2015). Recent population studies in the USA estimate that a minimum of 14% of adults diagnosed with cancer have dependent children (Weaver, Rowland, Alfano, & McNeel, 2010) and an estimated 30% of breast cancer patients are parents with children aged under 18 years old (Semple & McCance, 2010).

Parents with advanced cancer who have a poor prognosis represent a patient group at high risk of psychosocial distress. Until recently, research studies have predominantly focused on the early stages of disease (Zaider, Salley, Terry, & Davidovits, 2015). The emerging research suggests that this patient group face unique psychosocial issues that effects their wellbeing, parenting, healthcare choices, and family functioning. That is, parents with advanced cancer face multiple psychosocial stressors (Nadimi & Currow, 2008; Rainville, Dumont, Simard, & Savard, 2012; Zaider et al., 2015), and these stressors arise from simultaneously managing illness-related issues and contemplating the inevitability of death, while contending with parenting-related demands and concerns (Houldin & Lewis, 2006; Nadimi & Currow, 2008; Turner et al., 2007), change in roles (Elmberger, Bolund, & Lützén, 2002; Rose et al., 2009; Semple & McCance, 2010), financial issues (Rainville et al., 2012), and legal matters (Nadimi & Currow, 2008).

A multi-institutional prospective cohort study conducted in the USA (Nilsson et al., 2009)—the first known empirical study of its kind—found that adults with advanced cancer who are parenting minor children are more anxious, less at peace, and experience a worse quality of life in the last week of life compared to patients

without dependent children. These parents favour treatment options aimed at prolonging life as much as possible over those focused on relieving pain and discomfort (Nilsson et al., 2009; Zaider et al., 2015). Planning for their death is approached differently from their cohort without dependent children, with fewer having advance care planning arrangements in place (Nilsson et al., 2009). Emerging evidence from qualitative studies is beginning to confirm that parenting concerns are linked with their psychological distress and quality of life (Park et al., 2016). Parents' greatest concerns comprise how their children would cope with their death and the impact of their illness on their children's current emotional wellbeing.

Another strong theme emerging from recent research literature proposes parents with advanced cancer want guidance and reassurance from health professionals to address concerns relating to parenting competence and practical support needs (Swick & Rauch, 2006; Turner et al., 2007) including direct support with talking to their children about their diagnosis. Parents want educational resources specific to end-stage cancer and parenting to be provided at the point of diagnosis and suggest that a multidisciplinary approach to supportive care service provision be adopted to ensure support is more readily accessible to patients (Turner et al., 2007).

Psychosocial supportive care service provision is recognised as an integral element of cancer care (Cancer Australia, 2014) and palliative care (Larkin, 2010). Despite this, local and international clinical and research evidence indicates that parents with terminal cancer frequently fail to have their supportive care needs addressed in the healthcare setting (Helseth & Ulfsæt, 2005; Turner et al., 2007). Recent published international literature confirms that intervention research on parenting-focused psychosocial interventions within cancer care is still in its infancy (Ernst et al., 2013; Lewis et al., 2015) and even less is known about the composition of effective patient-centred psychosocial supportive care practices for parents with advanced cancer when curative treatment is no longer an option.

A systematic review of structured family-focused interventions targeting children of parents diagnosed with any stage of cancer (Niemelä, Hakko, & Räsänen, 2010) did not reveal any interventions that catered specifically for families where a parent was diagnosed with incurable end-stage cancer. One study (Thastum, Munch-Hansen, Wiell, & Romer, 2006) however, included parents with end-stage cancer but did not report parent outcome findings according to disease stage. More recently, a systematic review examining structured psychosocial interventions for families of palliative patients with minor children (Kühne et al., 2012) identified one program that reported on intervention outcomes for parents with end-stage cancer (Bugge, Helseth, & Darbyshire, 2009); other studies included parents with palliative-stage cancer but did not report parent outcomes (Kissane & Lichtenthal, 2008; Schmitt et al., 2007; Thastum et al., 2006) or focused on the evaluation of service implementation processes (Romer et al., 2007). The latest review targeting child-centred and family-centred interventions that focused on adolescents living with a parent with advanced cancer (Phillips, 2014) identified one intervention involving parents with incurable end-stage cancer (Bugge et al., 2009), as reported by Kühne et al., (2012).

Against this background, this rapid evidence assessment (REA) differs from previous reviews as its purpose is to: (a) identify published evaluation studies of any type of psychosocial intervention involving parents with incurable end-stage cancer who are parenting at least one child aged 0–18 years, and (b) synthesise the evidence describing the effectiveness of psychosocial interventions for parents with incurable end-stage cancer in addressing their psychosocial concerns and wellbeing.

Method

This REA—a streamlined systematic approach for synthesising research evidence (Khangura, Konnyu, Cushman, Grimshaw, & Moher, 2012)—was conducted in a transparent, systematic, and replicable manner.

Search strategy

The computerised primary databases of the Campbell Collaboration, Cochrane Central Register of Controlled Trials, Cumulative Index Nursing and Allied Health Literature (CINAHL), MEDLINE, PsycINFO, Scopus, and SocINDEX were searched. Grey literature was searched utilising computerised grey literature databases including CareSearch, mixed web sources, directories and clearing houses, Sociological Abstracts, Web of Science, WorldCat, Australian and Federal Government sources, and online Australian and international theses indexes. Relevant journals and reference lists were also hand searched including: *Journal of Palliative Medicine, Journal of Psychosocial Oncology, Journal of Psycho-Oncology, Palliative Medicine, and Psycho-Oncology*.

Selection criteria

A broad and inclusive search of keywords (titles, abstracts, and subject headings) and their database-specific variants was conducted in December 2015 in order to identify relevant intervention studies that combined terms for end-stage cancer, psychosocial interventions, parenting, and healthcare setting. The search strategy used and combined the following terms or analogues across the databases: (advanced, cancer, chronic, end-stage, incurable, neoplasms, palliative, palliative care, terminal* ill*) AND (clinical program*, counsel*, family-centred intervention, parent*-focused intervention, psycho- education, psychological intervention, psychosocial support*, therap*) AND (child-raising, child-rearing, father*, father–child, parent*, mother*, mother–child, parent–child, step- parent*) AND (cancer care, cancer cent*, hospice*, hospital, oncology service, outpatient).

No date, geographic location, or quality limits were set as evidence from a preliminary scope of the literature indicated a dearth of published evaluation studies. Searches were conducted from the commencement date of each primary database (e.g., PsychINFO: 1806–2015). Relevant journals were hand searched for the period 2005–2015 to identify if any current intervention studies had been

missed during the primary searches. Assistance was sought initially from the specialist librarians at The University of Melbourne to develop the key search terms. The search terms were further refined by reviewing the MeSH and key search terms used by published journal articles that met the inclusion criteria. All search and screening tasks were conducted independently by a single author (VS) according to the pre-determined selection criteria.

Inclusion criteria

Articles included met the following criteria:

- Population: Parents diagnosed with advanced cancer who were parenting dependent children aged [0–18] years; parental status (fulltime, part-time; biological, non-biological; single parenting, shared parenting);

- Intervention: Psychosocial interventions (e.g., counselling, psychoeducation, education, support groups); parent- and family-centred interventions only; any form of content (e.g., not limited to parenting or supporting children); conducted in an acute healthcare setting (inpatient or outpatient), hospice or community setting; any delivery method;

- Outcome: Any psychosocial outcome; primary outcomes targeted the parent with cancer (e.g., psychological health and wellbeing, parent–child relations, parental competence); and

- Studies: Intervention evaluation studies using any design methodology; published in peer-reviewed journal articles, government and nongovernment reports, conference papers, Australian and international theses; studies were available in the English language; full text articles were available.

Studies were excluded if the intervention outcome measures only focused on the children, the well parent, or the family unit (e.g., family functioning) and did not

include any outcome measures for the unwell parent. Publications were also excluded if the main outcome measures focused solely on caregiver and child bereavement rather than issues measuring the period of time before death. Empirical intervention study descriptions, abstracts of dissertations and conference proceedings, anecdotal reports, and reviews were excluded.

Quality assessment

As a result of the modest number of heterogeneous studies identified during an initial scoping review of the literature, no minimum quality criterion was set. A quality assessment of the two qualitative studies was undertaken using the validated Qualitative Research Quality Checklist (QRQC) (Saini & Shlonsky, 2012) while the quantitative and mixed methods studies were assessed with the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies (Jackson & Waters, 2005). One author (VS) appraised all of the studies and the second review was completed by one of the co-authors (AS and LJ). Findings were discussed and a concluding decision was made. Studies were not excluded on the grounds of poor quality.

Data extraction and synthesis

A systematic narrative approach was used to synthesise the diverse studies. The synthesis of outcomes was challenging due to the substantial heterogeneity in the types of outcomes assessed, measurements used, types of questions asked, study designs and sampling employed, and theoretical and analytic approaches used. As a result of these differences and the relatively small number of final studies in the review we elected to simply report quantitative findings and to narratively synthesise qualitative findings using thematic analysis (Bearman & Dawson, 2013). That is, we reviewed each of the studies and developed broad categories from these outcomes, which included parents' psychosocial concerns and supportive care needs as well as the perceived impact of the intervention on parents' psychosocial

wellbeing. Common themes within these categories were then identified utilising a general coding system. Owing to the inability to differentiate the outcomes of the parents with end-stage cancer from those who had varied stages of cancer (studies involving parents with varied cancer stages) the results were reported under two groups: (a) parents with incurable advanced cancer; and (b) parents with varied stages of cancer (including end-stage cancer). Given the current review focused on evaluations of psychosocial interventions engaging parents with incurable end-stage cancer (and searches were designed to specifically find these), only the reported outcomes for parents were assessed. Reported outcomes for their children and the healthcare professionals were omitted.

Results

Identification and selection criteria

The initial primary database search results (N = 937) were obtained: Campbell Collaboration (n = 14), CINAHL (n = 24), Cochrane (n = 350), PsycINFO (n = 78), MEDLINE (n = 113), Scopus (n = 350), and SocINDEX (n = 8). The preliminary grey literature and other sources identified a large number of initial articles (N = 1836): grey literature databases (n = 1796) and key journals (n = 40) (Figure 1). Relevance of the article was established by appraising the article title first. Where a determination for inclusion was not conclusive, the abstract was scrutinised and then if the study met inclusion criteria or this was unclear the full text article was retrieved and reviewed. Following this process, the resulting records (n = 61) were screened for duplicates and (n = 33) were removed. They included same studies published in different research articles or academic journals and duplicate journal articles. After scrutinising the remaining 28 articles, four studies satisfied the selection criteria. Of the 24 texts excluded, 20 were not classified as evaluative studies and four focused solely on parents with early stage cancer (stages 0–III) (Davey, Kissil, Lynch, Harmon, & Hodgson, 2013; Davis Kirsch, Brandt, & Lewis, 2003; John, Becker, & Mattejat, 2013; Lewis et al., 2015).

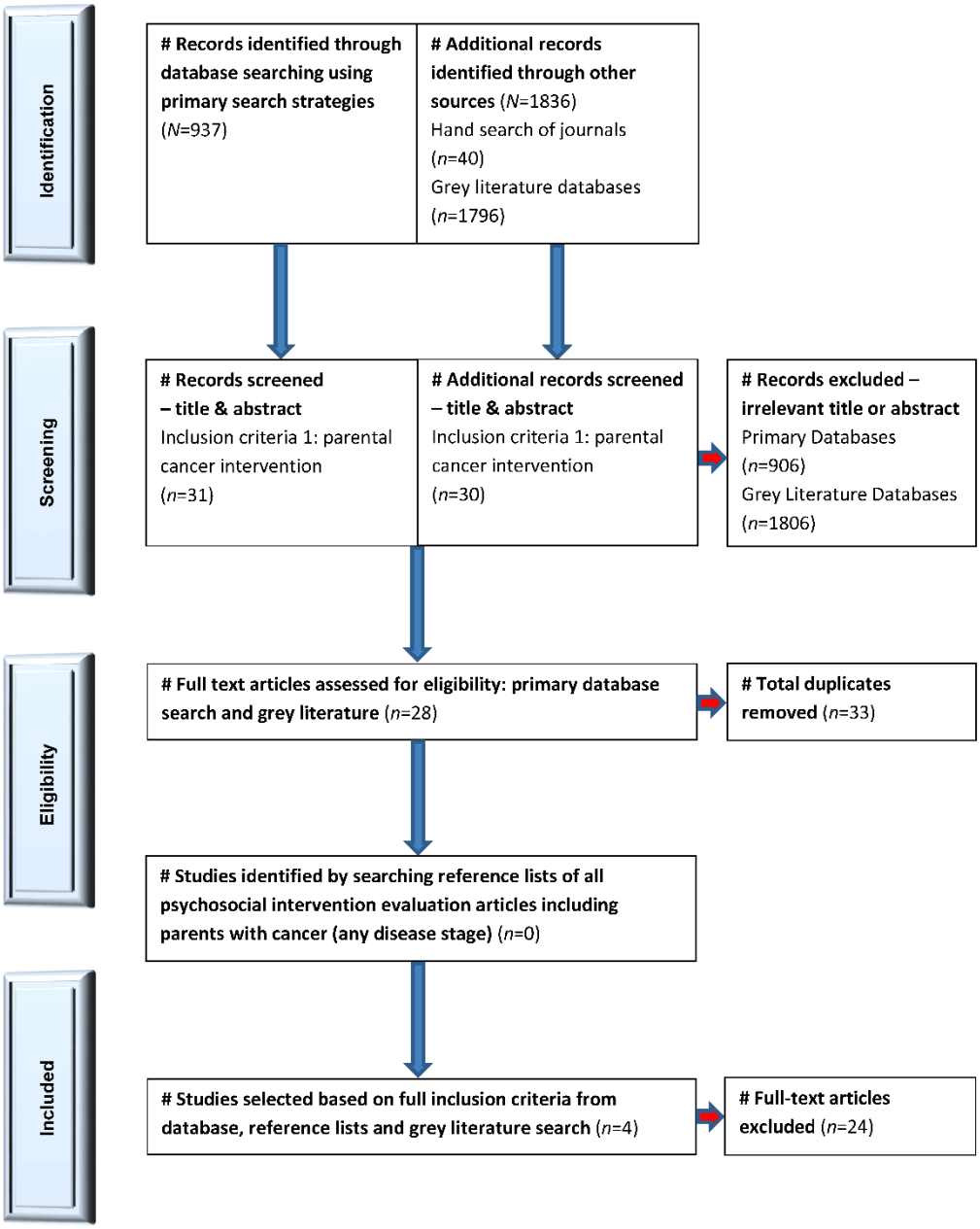

Figure 1. Flowchart – Rapid evidence assessment

Interventions study characteristics

Table 1 provides a summary of the psychosocial intervention program study characteristics. The quality of studies varied from weak to strong. All of the studies were developed and delivered in Europe: Norway (Bugge et al., 2009), Denmark and Germany (Thastum et al., 2006), Finland (Niemelä, Repo, Wahlberg, Hakko,

& Räsänen, 2012), and France (Landry-Dattée et al., 2016). There were two qualitative studies with no control group (Bugge et al., 2009; Landry-Dattée et al., 2016): a quantitative randomised controlled trial (Niemelä et al., 2012) and a semi-controlled mixed methods design study (Thastum et al., 2006). One of the studies focused exclusively on parents with end-stage cancer (Bugge et al., 2009) and the remaining three studies included—but was not limited to—parents with end-stage cancer (Landry-Dattée et al., 2016; Niemelä et al., 2012; Thastum et al., 2006). All four intervention programs shared the similarities of being structured, family-focused, child-centred, and time-limited.

The *'Family Talks in Cancer Care' Family Support Program* (FTCCP) study was exclusively designed for parents with terminal cancer and their children (Bugge et al., 2009). Two evaluation studies were part of larger research studies: the international multisite research study *Children of Somatically Ill Patients* (COSIP) (Thastum et al., 2006) and the *Struggle for Life* trial (Niemelä et al., 2012). The fourth study was a retrospective evaluation of closed parent–child support groups (Landry-Dattée et al., 2016). The hospital setting was the common intervention site (Bugge et al., 2009; Landry-Dattée et al., 2016; Niemelä et al., 2012) with the exception of the COSIP program (Thastum et al., 2006) which was primarily provided in the home setting, as per patient preference.

Table 1. Summary: Psychosocial intervention program evaluation studies

Intervention Name	Author, Year; Country; Quality Rating	1. Target group 2. Intervention type 3. Course 5. Site	Intervention Aims	1. Theory/Empirical Background 2. Study design 3. Participants 4. Comparison group	Measurement	Results/Findings: Parent Outcomes
'Family Talks in Cancer Care' Family Support Program (FTCCP)	Bugge et al., (2009); Norway; QRQC quality rating: good	(1) Parents with cancer & children aged [5-18] years (2) Psycho-education, counselling (3) Face-to-face, structured, manualised; 4 meetings pre-death, 1 post-death (4) Akershus University Hospital, Innlandet Hospital, & Ullevaal University Hospital	(1) Open communication (2) Parenting competence (3) Future planning	(1) Coping Theory; Family Resilience Theory (2) QUAL: in-depth interviews (3) Ill parents (n = 6); spouses (n = 7); children (n = 12) (4) No comparison group	Post Intervention (1) In-depth qualitative interviews	(1) Improved communication and confirmation of parenting competence (2) Identified resources inside/external to family; shared memory making and strengthening of relationships (3) Utilising help – Future planning and identified support needs; planning of palliative care phase: home/hospital
Focused Short-term preventive counselling Project for Families with a Parent with Cancer	Thastum et al., (2006); Denmark; EPHPP quality rating: strong	(1) Parents with cancer & children aged [8-15] years (2) Counselling (3) Face-to-face, structured, 5-6 family sessions; Session 1: parents only (4) Aarhus University Hospital	(1) Open communication (2) Coping processes (3) Parenting competence (4) Improve family functioning (5) Anticipatory grief	(1) Not stated (2) Mixed method design; standardised measures & semi-structured interviews (3) QUAN: Counselled (n = 24); Non-counselled (n = 16); QUAL: counselled (n = 24); counsellors (n = not stated) (4) Comparison group: Non-randomised non-counselling group – allocation based on refusal of counselling	Pre-Post Intervention (1) Beck's Depression Inventory (BDI-II)[Self-report; 21-item]; (2) Self-report Family functioning: The McMaster Family Assessment Device (FAD) [self-report; 53-item] (3) Post Intervention (4) Questionnaire of the Opinion of the Counselling Service (QOCS) (5) Semi-structured qualitative interviews	(1) Quantitative: Decrease in depression scores; no improvement in fathers' depressive symptoms; positive changes in family functioning (2) Qualitative: Confirmation of parenting competence; greater understanding and awareness of family members' emotions and reactions; improved family cohesion; normalisation and a sense of legitimacy of own feelings

Intervention Name	Author, Year; Country; Quality Rating	1. Target group 2. Intervention type 3. Course 5. Site	Intervention Aims	1. Theory/Empirical Background 2. Study design 3. Participants 4. Comparison group	Measurement	Results/Findings: Parent Outcomes
Let's Talk about the Children (LT) & Family Talk Intervention & (FTI) Programs	Niemelä et al., (2012); Finland; EPHPP quality rating: strong	(1) Parents with cancer & children aged [8-17] years (2) Psycho-education, counselling (3) Face-to-face, structured; 6-8 sessions (4) Oulu Hospital, Central Ostrobothnian Central Hospital, Tampere University Hospital, Vaasa Hospital & Kainuu Central Hospital	(1) Support parenthood (2) Support psychosocial well-being of parents & children	(1) Clinical practice; Children's risk during parental mental illness (Beardslee, 1998) (2) Family cluster, RCT; standardised measures (3) Intervention group: Ill parents (n =7); Spouses (n = 7); Control group (n = not stated) (4) Comparison group: randomised - a Finnish general population sample (FGP) and a Finnish psychiatric outpatient sample (FPO)	Baseline, Interval follow-ups (4mth, 10mth, 18mth) (1) Symptoms Checklist (2) 90 for Adults (SCL-90) [Psychiatric; self-report; 90-item] (3) Global Severity Index (GSI) [self-report; derived from SCL-90] (4) Post Intervention (5) Intervention feedback questionnaire [self-report]	(1) Only data: 4 months post intervention - parents' psychiatric symptoms decreased to same level as general population
Child-parent support group	Landry-Dattée et al., (2015); France: QRQC quality rating: weak	(1) Parents with cancer & children aged [4-18] years (2) Peer Support Group (3) Face-to-face; structured; closed group: two 2hr sessions/2 week interval (4) Gustave Roussy Cancer Centre	(1) Facilitate communication (2) Help support child & their symptoms	(1) Psychoanalytic Theory; Clinical Practice (2) QUAL: 12 year retrospective semi-directed interviews with parents & family (3) Ill parents (n = 40); spouses (n = 21); children (n = 19) (4) No comparison group	Post Intervention (1) Semi-directed qualitative interview	(1) Satisfaction with program (2) Helped facilitate communication about cancer with children; peer support; parents perceived reduced distress symptoms in children

The theoretical and empirical frameworks guiding the studies were minimally stated. The primary prevention intervention model for families with parental mental illness (Beardslee, Gladstone, Wright, & Cooper, 2003; Siegenthaler, Munder, & Egger, 2012), was largely drawn on for both the FTCCP (Bugge et al., 2009) and the *Let's Talk about the Children and Family Talk Intervention* (LT & FTI) programs (Niemelä et al., 2012). Based on a longitudinal large-scale efficacy study of 2.5 years, the brief family-based clinician-facilitated manual-based intervention model was shown to produce positive behavioural and attitudinal outcomes for both the unwell parent and their children, with increased parental change leading to greater child change over time (Beardslee et al., 2003). Family resilience theory (Allison et al., 2003) and coping theory for children (Libo & Griffith, 1966) were also reported to inform the FTCCP (Bugge et al., 2009). A psychoanalytic framework (Kirshner, 2006) underpinned the parent–child support group intervention (Landry-Dattée et al., 2016). Developmental theory provided a foundation for all program interventions (Bugge et al., 2009; Landry-Dattée et al., 2016; Niemelä et al., 2012; Thastum et al., 2006) with all interventions adopting a child-centred approach that encompassed support for parenthood. A child-centred approach in the parental cancer context focuses on providing psychosocial support to actively promote the wellbeing of the children whose parents have cancer (Niemelä, 2012), which may be associated with improvements in psychosocial wellbeing for both children and parents (Niemelä et al., 2010).

Facilitating open communication between the parent and their children about cancer, strengthening parenting competence and supporting the psychosocial wellbeing of the child (Bugge et al., 2009; Landry-Dattée et al., 2016; Niemelä et al., 2012; Thastum et al., 2006) were the common aims reported across the studies. Further, three intervention programs shared the goal of introducing open discussions of possible death and anticipatory grief (Bugge et al., 2009; Landry-Dattée et al., 2016; Thastum et al., 2006). The FTCCP study (Bugge et al., 2009) explicitly aimed to help the family plan for the future and structured a post

parental death bereavement intervention for the family, unlike the other programs. Clinical practice experience and identified gaps in service provision were reported as driving the development of two of the programs (Bugge et al., 2009; Landry-Dattée et al., 2016). Examples of clinical experience were reported to include health professionals observing reticence of parents in communicating to their children about cancer and the impact of this on the family (Landry-Dattée et al., 2016) and parent-reported difficulties of coping alone (Bugge et al., 2009).

Cancer population

Homogenous and mixed cancer populations participated in the included studies. Cancer type was specified in two studies (Bugge et al., 2009; Niemelä et al., 2012) and included bowel/intestinal cancer, brain cancer, breast cancer, hereditary angioneurotic oedema, ovarian cancer, lung cancer, melanoma, pancreatic cancer, and thyroid cancer. Three studies (Landry-Dattée et al., 2016; Niemelä et al., 2012; Thastum et al., 2006) involved participants with varying stages of cancer disease progression, inclusive of incurable end-stage cancer.

The FTCCP (Bugge et al., 2009) was the sole study to record sociodemographic data in detail. The program study engaged four fathers and two mothers (one mother and one father deceased before study completion) within the age range of 38–54 years old and a mean age of 42 years (Bugge et al., 2009). The relationship status was reported as: divorced (n = 1); divorced and re- partnered (n = 2); and partnered/married (n = 3). Family size varied from one-child families to three-child families, with two-child families most common (n = 4). Two programs reported diverse family structure, including step-parents (Thastum et al., 2006), divorced and re-partnered parents (Bugge et al., 2009). Overall, females comprised the dominant gender (75% and higher) in three of the intervention studies (Landry-Dattée et al., 2016; Niemelä et al., 2012; Thastum et al., 2006). Socioeconomic status, cultural background, education, and class information was not captured by any of the studies.

Recruitment and attrition

One study (Bugge et al., 2009) published data on parents who declined to engage in the study, stating illness progression as the primary rationale. Detailed attrition data were collected in two studies: 53% participants completed the *Struggle for Life* trial (Niemelä et al., 2012) and 67% finished the FTCCP study (Bugge et al., 2009). Death of the ill parent accounted for mid-study attrition (Bugge et al., 2009; Niemelä et al., 2012; Thastum et al., 2006); no other reasons were provided.

Interventions outcomes

Parents with incurable end-stage cancer

The FTCCP study (Bugge et al., 2009) was the sole intervention program identified in this review designed exclusively for parents with incurable advanced cancer. A key theme underpinning the results was parents' long-term unmet need for health professional support to help navigate their psychosocial challenges. Parents wanted: help to manage the intense personal discomfort of dealing with an incurable cancer diagnosis; an approximation of their length of life so they could prepare their children and future plan; to share the responsibility with health professionals of raising the topic of their impending death with their children; confirmation they had positively supported their children; help identifying resources within and external to the family unit; support with future planning for their children; and assistance planning for the terminal phase with regards to parenting and end-of-life care (Bugge et al., 2009). Parents valued their healthcare being provided in a child-friendly way so their children could be with them throughout the dying process.

Parent-reported intervention impact was expressed by parents' experience of the program and outcomes were categorised into three main themes (Bugge et al., 2009). They included: (a) open and honest communication; (b) reframing the

illness crisis using family strengths; and (c) accessing and using support. The parents' experiences suggested the program may have supported family resilience by increasing their use of strategies and processes to deal with their challenges, and using family strengths to reframe the crisis and prepare for the future. Parents also reported a better understanding of their children and enhanced parent–child bonds and valuing a child-friendly healthcare environment.

No studies based on quantitative data were identified.

Parents with varied stages of cancer (including end-stage cancer)

The qualitative component of the studies captured parent-reported data regarding their motivation for pursuing psychosocial supportive interventions. Parents often sought guidance from health professionals for individual, parent, and family wellbeing, notably: how best to inform their children about the cancer and support them (Landry-Dattée et al., 2016; Thastum et al., 2006); confirmation of their parenting competence (Landry-Dattée et al., 2016; Thastum et al., 2006); and support to address the lack of communication about problematic aspects of their illness, interpersonal conflict between family members, and to deal with the changing of roles within the family (Thastum et al., 2006).

The family support group program achieved its aims with 54% of parents perceiving the intervention facilitated improved intra-familial communication (Landry-Dattée et al., 2016). Parents in receipt of the short-term preventive counselling intervention reported the following gains: confirmation of being a good enough parent; enhanced awareness and understanding of other family members' emotions and responses; achieving a feeling of normalisation and legitimisation of their own feelings; and enhanced family relationships (Thastum et al., 2006).

Two studies using objective measures reported improvements in parents' psychological functioning by measuring parents' depression and anxiety levels

(Niemelä et al., 2012; Thastum et al., 2006). Results yielded from the short-term counselling study showed that mothers—but not the fathers—became significantly less depressed during the counselling period (Thastum et al., 2006). The gender difference was explained in part by the fact that depression at baseline was higher for mothers, independent of whether they were the patient or the spouse (Thastum et al., 2006). Following 4 months of engaging in a randomised controlled treatment trial using two psycho-education and counselling interventions (Niemelä et al., 2012), parents with cancer experienced a decrease in psychiatric symptoms to the level as experienced in the general population. Data presented in the mixed-cancer-stage studies were not described in relation to disease prognosis or the staging of parental cancer.

Parent-reported psychosocial practice recommendations

Parent-reported practice recommendations about how the interventions could better meet their psychosocial support needs were collected in three studies (Bugge et al., 2009; Landry-Dattée et al., 2016; Thastum et al., 2006). Parents with incurable advanced cancer and their families (Bugge et al., 2009) proposed numerous key recommendations for enhanced psychosocial support. These were: increased emotional support during hospitalisation; interventions that include bereavement support; program staff seeking parents' ideas and opinions before presenting a solution to a problem; hospital staff awareness of existing family support services; acknowledging diver- gent parenting views within families where parental relationships are fractured; and healthcare practice guidelines for supporting such families (Bugge et al., 2009).

Regarding program continuity, parents of varied cancer staging expressed they wanted more than six counselling sessions and also follow-up sessions designed to review how the family was maintaining the changes made during counselling (Thastum et al., 2006). They also wanted programs to be integrated into

mainstream healthcare and available to all parents who receive a poor prognosis (Bugge et al., 2009; Landry-Dattée et al., 2016).

No recommendations were reported in the quantitative-based study (Niemelä et al., 2012).

Discussion

Our REA has revealed several important findings. Overall, it confirms the scarcity of published studies on evidence-based psychosocial intervention programs addressing the supportive care needs of parents with incurable end-stage cancer. Of the four intervention studies included in this review, only one psychosocial intervention program was specifically tailored for parents with incurable metastatic cancer and reported intervention outcomes for parents (Bugge et al., 2009). This finding—along with related intervention reviews (Kühne et al., 2012; Phillips, 2014)—strongly indicates that further intervention research is needed. Without high quality research, the delivery of patient-centred evidence-informed psychosocial supportive care is compromised.

We found that setting the search inclusion criteria more broadly to include all types of psychosocial intervention studies did not result in a large number or diverse range of psychosocial intervention studies being found. All interventions were delivered as child-centred, family-focused, structured, and time-limited programs. This finding was consistent with current empirical evidence which affirms parents' primary concerns lie foremost with their children's wellbeing when they face a terminal cancer diagnosis and our growing understanding that parental cancer affects the whole family. Being structured and time-limited, interventions can be adapted across healthcare settings and delivered by healthcare professionals after a short period of training. This model fits well with contemporary integrative cancer care (Bruera & Hui, 2010) which has moved from a single-discipline approach to an interdisciplinary approach.

Drawing conclusions about how effective the interventions were in addressing the supportive care needs of parents with incurable end-stage cancer was difficult. There were diverse variations in experimental design and outcome measures, and sample size was small. Determining which reported outcomes were directly related to parents with end-stage cancer for the three studies that recruited parents with mixed cancer diagnoses (Landry-Dattée et al., 2016; Niemelä et al., 2012; Thastum et al., 2006) was not possible. Factors such as lack of data on sociodemographic diversity, as well as gender bias in sampling, rendered us unable to make explicit recommendations with respect to program suitability or validity for common practice. Attrition rates also had a noted impact on reported parent outcomes by decreasing the sample size and resulting in incomplete data collection (Bugge et al., 2009; Niemelä et al., 2012). Yet, limiting attrition of patients who are terminally ill is particularly challenging in such psychosocial studies, which must balance the need for adequate sample size with consideration of ethical research practices and a limited (but unknown) time with which to interact with participants. Both the FTCCP study (Bugge et al., 2009) and LT & FTI study (Niemelä et al., 2012) reported challenges in sampling and data collection, but managed to yield quality intervention evaluation data.

Various research design strategies were implemented to achieve quality data. For example, recruitment for the qualitative FTCCP study (Bugge et al., 2009) continued until the emerging data of the parents' experiences collected during in-depth interviews reached a point of saturation and variability; this occurred after 13 families were interviewed. Qualitative research (Guest, Bunce, & Johnson, 2006) has shown rich and quality data can be obtained from small samples of relatively homogenous populations. The early phase pilot evaluation LT & FTI study (Niemelä et al., 2012) utilised a widely used psychiatric self-report inventory—the Symptoms Checklist 90 for adults (SCL-90) that was specifically validated on the Finnish population. Information obtained from baseline data and the 4-month follow-up assessment was sufficient to conclude early on in the intervention that it had a beneficial impact on parents' psychological wellbeing. Importantly, it

demonstrated that providing structured child-centred interventions did not have an adverse effect on parents' psychosocial wellbeing.

Despite the limited evidence found in this review, the qualitative FTCCP study (Bugge et al., 2009) provided valuable insights into the specific and unique psychosocial concerns of parents with incurable end-stage cancer. It highlighted which supportive care practices can be of benefit to them psychologically, emotionally, and practically. Predominantly, parents were confronted by their palliative status and parenthood. They wanted to be a good parent yet were unsure how to balance open and honest communication with their feelings of protectiveness. Discussing disease progression and death—knowing how, when, and what to communicate—was a common challenge experienced. The task of planning ahead for their children's future—for which they would not be present—was very difficult. Parents reported they wanted healthcare professionals to share the responsibility of discussing these matters with their children. These issues align with those documented in contemporary research literature (Fearnley & Boland, 2017). To address such concerns while catering for individual needs within each family, the FTCCP was delivered as a tailored program. Outcomes indicate this model was helpful; child–parent relationships were strengthened and parenting competence improved. Parents commended the direct practical support they were given to plan for their children's future, as well as the facilitated memory-making activities undertaken with their children. While the FTCCP study is not generalisable to the broader population of parents with incurable advanced cancer due to methodological limitations such as small sample size (Bugge et al., 2009), it provides a foundation from which future interventions can be built upon and evaluated.

The psychological impact of psychosocial interventions on parental psychological wellbeing was evaluated in two studies using formal instruments. The study conducted by Niemelä et al., (2012) revealed promising preliminary results with a reduction of parental psychiatric symptoms at the 4-month post intervention

follow-up point. However, the interventions were not the primary clinical treatment method, with parents receiving medication, other treatment, and professional support during the trial period. No data were yet available from the 12- and 18-month follow-up period post intervention, reducing the reliability of the findings. For the effectiveness of most preventive interventions to be quantitatively measured, data collection needs to be collected over a longer follow-up period (Niemelä et al., 2010). Achieving this can be challenging given the inexorable progression of the disease. Quantitative data from the short-term preventive counselling project (Thastum et al., 2006) showed a significant decrease in depression scores of parents post intervention compared to the non-randomised control group. Qualitative themes also revealed parents experienced significant gains regarding parenting competence and child– parent relationships. The use of a non-randomised control group was reported by the study's authors as a design limitation and a source of unknown and potentially important selection bias; however, this decision aligns with sensitive and ethical research practice.

The 12-year retrospective parent–child support group evaluation study (Landry-Dattée et al., 2016) was the only intervention study designed as a family-based peer support group. Parents reported the two-session group helped facilitate open communication about cancer between themselves and their children. The study was solely reliant on parents' memories from as long as 10 years prior. Given the inconsistency of memories over time (Landry-Dattée et al., 2016) and the biased and non-representative participant sample used, the effectiveness of this intervention is unclear. Conducting a prospective study capturing real-time data would produce more reliable results and would enable those facing an imminent death to have the opportunity to not only receive a potentially beneficial intervention but also make an invaluable contribution to the research literature. Exploring the effectiveness in response to the identified needs of these parents is important.

Strengths and limitations

This is the first known REA to identify and synthesise the evidence describing the effectiveness of psychosocial interventions for parents with incurable advanced cancer in addressing their psychosocial concerns and wellbeing. The search and evidence synthesis processes were transparently reported and it is likely that the relevant published studies in this area have been located. Several relevant journals were hand-searched and keyword searches with a wide range of terms were used. Studies were included in the review where cancer was described as "advanced" but a distinction had not been made whether it was chronic or end-of-life stage. Irrespective of the systematic methodology adopted and the broad search terms used, there was limited evidence available to draw on. The themes arising from the data suggest that family-focused psychosocial interventions can have beneficial psychological and social outcomes for parents with a cancer diagnosis. Confirmation of parenting competence, improved child–parent communication and family relationships, and achieving a feeling of normalisation and legitimisation of their own feelings were the primary gains reported by parents across the four studies.

Future research

A broad array of research is required to build high quality evidence to determine which psychosocial interventions best meet the supportive care needs of parents with incurable end-stage cancer. We require data on the preferred intervention modalities of this patient group (e.g., face-to-face, online, or phone) and the optimal timing of these interventions. All studies included in this REA were delivered face-to-face, and all but one (Thastum et al., 2006) alluded to issues regarding the optimal timing and length of the interventions. Controlled trials should be limited to comparative effectiveness studies that test what is provided, when, how, and for how long. Given the dynamic nature of cancer disease progression during the palliative stage, multiple cross-sectional studies would also

be beneficial in gathering evidence about which stage of the terminal phase might be most critical for intervention as well as the associated practices that dying parents and their families would find most beneficial. Investigating how family-focused psychosocial intervention programs could be integrated as part of routine care in the acute healthcare setting would be another important and useful step forward in this field of research.

Conclusion

Published psychosocial intervention efficacy studies targeting parents with incurable end-stage cancer are scarce. There are no high quality quantitative studies that specifically address outcomes for this parent group. There are also very few qualitative studies that detail their experience. Nonetheless, these limited findings suggest that family-focused approaches can potentially provide beneficial psychosocial outcomes for parents with cancer. In order to strengthen the body of evidence, there is a pressing need for continued intervention research to be undertaken to address the known and unmet psychosocial needs of parents with incurable end-stage cancer.

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Focus of the research

Cancer is one of the leading causes of death worldwide (WHO, 2018) and unlike many life-threatening illnesses, it causes premature impairment and death for parents with young families (Park et al., 2016). With life being prolonged due to improved medical cancer care (National Cancer Institute, 2019) and the delay of parenthood until later life (Gotze et al., 2017; Inoue et al., 2015), it is anticipated that the number of young families living with IESC will increase. Research in the field of parental cancer continues to emerge and current evidence indicates that parents—including co-parents—struggle with pressing parenting concerns during the IESC phase (Park et al., 2015). While many families are resilient and adapt well to the changes, the research findings indicate that parents and their children are at high risk of psychosocial distress, more so than families facing early-stage cancer and the general population.

Quality interdisciplinary psychosocial supportive care is now recognised as an integral element of cancer and palliative care and family-inclusive psychosocial interventions are increasingly being implemented to prevent and alleviate distress and undue suffering of patients and their families (Cancer Australia, 2014; Larkin, 2010). However, international research and empirical evidence suggest that the parenting support needs of patients facing advanced cancer are infrequently addressed in the healthcare setting (Turner et al., 2007a). Studies indicate that parents with IESC have expressed a need to receive health professional support and guidance with parenting-related issues; however, accessing assistance continues to be a challenge for many families.

Like many other areas in parental cancer literature, studies exploring what parenting interventions are delivered as an integrated element of routine hospital-based palliative cancer care are relatively limited. Parental cancer intervention research lags behind descriptive research (Kühne et al., 2012). Several studies exploring medical and nursing perspectives of parenting-related supportive care

practice have identified various factors that influence practice delivery (Arber & Odelius, 2018; Dencker et al., 2017), however a broader interdisciplinary perspective is required to develop a more comprehensive insight into their perspectives of parenting supportive care and factors influencing optimal parenting supportive care practice. In the spirit of the patient-centred healthcare principle of responding to healthcare consumers' needs (Kvåle et al., 2008), it is important to build on existing research to explore from patients' and co-parents' experiences and perspectives—their parenting support needs, hospital-based parenting-related support and insights into how supportive care responses can be enhanced to help alleviate distress for them and their children.

Research questions, design and methods

This study seeks to build on existing evidence to enrich the understanding of parenting supportive care practice provided as part of routine hospital-based palliative cancer treatment to adult patients who are raising minor-aged children, and parent and multidisciplinary health professional perspectives of which factors influence optimal practice and how parenting supportive practice can be improved. To achieve this, the thesis addressed the following questions.

The overarching research question (RQ) is:

> What are the parenting supportive care services offered as part of routine hospital-based palliative cancer care to adult patients raising minor-aged children?

The three sub-questions are:

> RQA: What documented parenting supportive care is provided to adult hospital patients with IESC who are parenting children up to 18 years old and receiving palliative care treatment?

RQB: What are multidisciplinary health professional perspectives on the parenting experiences and support needs of patients (and co-parents) diagnosed with IESC and factors influencing optimal parenting supportive care?

RQC: What are the perspectives of patients diagnosed with IESC and their families of hospital-based parenting related supportive care, their experiences and supportive care needs, and what factors facilitate and hinder optimal parenting supportive care?

Guided by the principles of pragmatism (Christ, 2013; Creswell, 2014) an exploratory mixed methods sequential design (Creswell, 2015) underpinned by a practice-based research approach (Dodd & Epstein, 2012) was selected. Three study phases were conducted in sequential order; a quantitative study followed by two qualitative studies.

The quantitative phase I study used clinical data mining (CDM) methodology (Epstein, 2001) to retrospectively collect data from 74 patients' medical records (diagnosed with IESC and parenting a minor-aged child). Descriptive statistical analysis (VanderStoep & Johnston, 2008) was used to interpret the data. The phase II study comprised interviews with a total of 12 hospital-based multidisciplinary health professionals using 1 focus group (Krueger & Casey, 2000) and two semi-structured interviews (Rapport et al., 2009–2010). Semi-structured interviews were conducted with eight hospital patients (diagnosed with IESC and parenting a minor-aged child) and four co-parents for the phase III study. Transcripts from the audio recordings from the phase II and III studies were analysed individually using thematic analysis (Braun & Clarke, 2006). Quantitative and qualitative findings from the phase I–III studies were then integrated using a narrative approach. Further details on research design and methodology are provided in Chapters 2–5.

Ethics

Multisite Low Risk Human Research Ethics approval (EC00235) was obtained from Peter MacCallum Cancer Centre, Melbourne Victoria for the Phase I study. Multisite ethics approval was required because one palliative service provided at the metropolitan hospital where the research was undertaken operated in partnership with another hospital. The Western Health Low Risk Ethics Committee, Melbourne Victoria granted approval (HREC/17/WH/59) for Phase II and Phase III studies.

Thesis structure

This thesis is presented as a series of three interconnected studies. Collectively, the three studies explore the hospital-based parenting supportive care response to hospital patients diagnosed with any type of incurable end-stage cancer (IESC) and parenting at least one child aged 18 years or younger.

Chapter 1 has provided an introduction of the motivation for this study, a review of the literature including parenting-related concerns when families with minor-aged children live with parental IESC and healthcare responses to addressing parenting supportive care needs, and a review of the parenting intervention research specific to these families. It sets out the project aim and research questions of the present study.

Chapter 2 describes the project design and methodology used for the three study phases.

Chapter 3 covers the phase I study that explores the clinical, sociodemographic and psychosocial profile of adult hospital patients who are parenting minor children and receiving hospital-based treatment, and parenting supportive care practice offered as part of routine healthcare treatment. The study is presented in journal article manuscript format.

Chapter 4 details the phase II study which examines multidisciplinary health professional perspectives of patient and co-parent parenthood experiences and parenting supportive care needs and factors influencing optimal parenting supportive care in the hospital context. Details are presented in journal article manuscript format.

Chapter 5 presents the third study that investigates the lived experiences of patients and co-parents—covering parenthood, parenting support needs, hospital-based parenting supportive care service, and their perspectives of factors influencing optimal parenting supportive care delivery. Details are presented in journal article format.

Chapter 6 discusses the results in relation to the research questions, with considerations given to current literature, policy and practice. Strengths and limitations of the project are reviewed and areas for future research are outlined. Considerations for how practice might be changed at the organisation and practitioner levels to better meet the parenting-related supportive care needs of patients with IESC and their families are defined. The chapter concludes with a summary of the proposed contributions made by the research project.

Definitions

This section provides definitions of terms used throughout this paper. For the purpose of this study the following definitions will apply.

Advanced cancer[1]: Cancer that is unlikely to be cured or controlled with treatment. The cancer may have spread from where it first started to nearby tissue,

[1] Definition from the National Cancer Institute Dictionary of Cancer Terms. Retrieved from https://www.cancer.gov/publications/dictionaries/cancer-terms/def/advanced-cancer

lymph nodes, or distant parts of the body. Treatment may be given to help shrink the tumour, slow the growth of cancer cells, or relieve symptoms.

***Co-parent*:** Any adult who is sharing the primary caregiving role of the children with the parent/patient diagnosed with IESC.

***Incurable end-stage cancer (IESC)*:** IESC is defined as any Stage 4 cancer (all cancer types except brain tumours) and any Grade 4 cancer (brain tumours), also referred to metastatic cancer or advanced cancer, but where curative treatment is no longer the goal of care.

Parent: Any adult who is the primary carer of at least one minor-aged child. The definition includes the child's biological parent or other persons with a primary parenting role including grandparents, step-parents, foster parents and other guardians.

Parenting: Caregiving role of children performed by a parent. The parenting role may occur on a full time or part time basis; and be performed solely or as a shared responsibility. The parent may reside with the children or elsewhere.

Prognosis[2]: The likely outcome or course of a disease; the chance of recovery or recurrence.

Supportive care[3]: An umbrella term used to describe services that may be required by those affected by cancer. It includes self-help and support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care. Supportive

[2] Definition from the National Cancer Institute Dictionary of Cancer Terms. Retrieved from https://www.cancer.gov/publications/dictionaries/cancer-terms/def/prognosis
[3] Definition from the Department of Health Victoria. Retrieved from https://www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-services-framework/supportive-care

care in cancer refers to the following five domains: physical, psychological, social, information and spiritual needs.

CHAPTER 2

Methodology

Overview

Chapter 2 explains the thesis design, methodology and research questions. The methodology for each study phase are detailed in Chapters 3–5.

Introduction

This research study was a practitioner-driven inquiry focused on direct hospital-based parenting-focused psychosocial supportive care practice with adult patients diagnosed with IESC who are parenting one or more children aged 18 years or younger. A critical review of the research literature (as examined above) confirmed gaps in this field of supportive care research. Given the dearth of research evidence, an exploratory practice-based research (Epstein, 2001) approach was adopted using a mixed methods (MM) sequential research design (Creswell, 2014). Exploratory designs encourage innovative investigation into previously unexplored areas, offer flexibility of data sources, enable engagement with participants on sensitive and challenging topics in a way that is responsive to their individual circumstances, and help identify avenues for future research (Hogden, Greenfield, Nugus & Kiernan, 2012). The research study comprised three connected study phases; each phase was conducted individually and in sequential order. The initial study phase results helped inform the interview questions posed in the phase II and III studies, and the phase II study together with the phase I results guided the interview questions for the phase III study. A comprehensive multi-perspective of the parenting supportive care needs of patients and co-parents living with IESC and hospital-based psychosocial supportive care practice was obtained—from documented evidence in patients' medical records and first-hand accounts from multidisciplinary health professionals delivering hospital-based parenting supportive care and healthcare consumers—patients and co-parents—in receipt of it.

Aim and research questions

Research aim

The aim of the thesis was to explore:

Parenting supportive care practice provided as part of routine hospital-based palliative cancer care to adult patients who are raising one or more minor-aged children.

Research questions

One overarching research question and three sub-questions guided this study. The research questions (RQ) were:

> What are the parenting supportive care services offered as part of routine hospital-based palliative cancer care to adult patients raising minor-aged children?

The three sub-questions are:

> RQA: What documented parenting supportive care is provided to adult hospital patients with IESC who are parenting children up to 18 years old and receiving palliative care treatment?
>
> RQB: What are multidisciplinary health professional perspectives on the parenting experiences and support needs of patients (and co-parents) diagnosed with IESC and factors influencing optimal parenting supportive care?
>
> RQC: What are the perspectives of patients diagnosed with IESC and their families of hospital-based parenting related supportive care, their experiences and supportive care needs, and what factors facilitate and hinder optimal parenting supportive care?

Research design, setting and participants

Research design

The improved accessibility of practice research to healthcare practitioners through the development of researcher-practitioner partnerships (Sim et al., 2018) inspired this research project. Therefore, pragmatism (Creswell, 2014) was chosen as the overarching research paradigm and an exploratory sequential mixed methods research design was developed. Producing socially useful knowledge (Biesta, 2010) and conducting research using a grounded practice research approach (Dodd & Epstein, 2012; Epstein et al., 2015) were particularly important for this research project. While many forms of pragmatism exist (Creswell, 2014), it is generally acknowledged that different realities exist and all are open to empirical inquiry (Creswell & Plano Clark, 2007; Rorty, 1999). Research is influenced by various contexts (including social, political and historical) with a focus on the practical implications of inquiry—finding solutions to real world problems (Creswell, 2014). Pragmatism is commonly associated with mixed methods research (Creswell et al., 2007) that is often utilised in healthcare and social science research (Guetterman, Fetters & Creswell, 2015). Research questions and methods are driven by the social purpose of the research (Long, McDermott & Meadows, 2018) and quantitative and qualitative forms of inquiry are viewed equally valuable for their capacity to help achieve a desired aim of producing a positive change in the world (Bishop, 2015). Exploratory designs enable innovative inquiry of previously unexplored topics, helping to develop a greater understanding of the area of research as well as identify avenues for further investigation. From its inception, this research study was born from clinical practitioners' curiosity, knowledge and reflections on a real-world clinical issue and was driven by the purpose of generating practical and relevant understandings of the research issue and the interest in offering novel information that could be used together with existing evidence to assist with the improvement of clinical practice to better address the parenting supportive care needs of parents facing IESC. A mixed methods design was chosen for its known

capacity to provide a rich and deep understanding of this healthcare issue by gaining a more in-depth understanding of issues and hearing the voices of participants (Guetterman, Fetter & Creswell, 2015) through the collection and synthesis of quantitative and qualitative data (Creswell, 2014). It draws on the strength of both approaches using inductive and deductive methods (Creswell & Plano Clark, 2011) that are increasingly being used by contemporary health services researchers (Ivankova & Kawamura, 2010; Klassen, Creswell, Plano Clark, Clegg Smith & Meissner, 2012; Zhang & Creswell, 2013). This exploratory research employed a holistic triangulation methodology (Turner, Cardinal & Burton, 2017). Specifically, three research strategies and populations were used to obtain unique insights and convergent and divergent perspectives (Jick, 1979), to provide a more comprehensive and contextual understanding of parents' parenting experiences during the IESC phase, their supportive care needs and hospital-based parenting supportive care practice. Systematically gathered descriptive information from different sources such as management information systems (e.g., patient medical records) and interviews with providers (e.g., health practitioners) and clients (e.g., patients and co-parents) can assist in identifying the nature of clients' problems and how interventions are experienced by clients and providers (Shlonsky & Mildon, 2014). Examination of the clinical issues was informed by clinical knowledge, systematic exploration of the data and thorough analysis of the multiple data sources (Haase, Thomas & Gifford, 2016).

The sequential three-phased study research design (Figure 1) was developed to capture different and unique perspectives of the research issue and comprises three unique but interrelated studies:

> Phase I study: A quantitative retrospective exploration of the clinical, sociodemographic and psychosocial profile of this patient subgroup and routine hospital-based psychosocial practice responses to their parenting-related support needs.

Phase II study: A qualitative exploration of multidisciplinary health professional perspectives of patients' and co-parents' parenting supportive care needs and hospital-based psychosocial service responses including factors influencing optimal parenting supportive care delivery.

Phase III study: A qualitative study examining patient and co-parent experiences of parenting and supportive care needs during the IESC phase, and their viewpoints on hospital-based parenting supportive care provision including factors influencing optimal care and how service can be improved to better meet their support needs.

Each phase was conducted individually in sequence, with data collection, analysis and the key findings reported independently (Chapters 3–5). The findings from the phase I study helped to inform the interview questions posed in the phase II study; the findings of phases I and II guided the phase III study interview questions. The key findings from each study phase was synthesised (Guetterman et al., 2015) to generate new insights and inferences (Creswell, 2015; Creswell et al., 2011). The project findings provide ideas for future research and data to contribute towards strengthening policy and practice at the organisation and health professional levels.

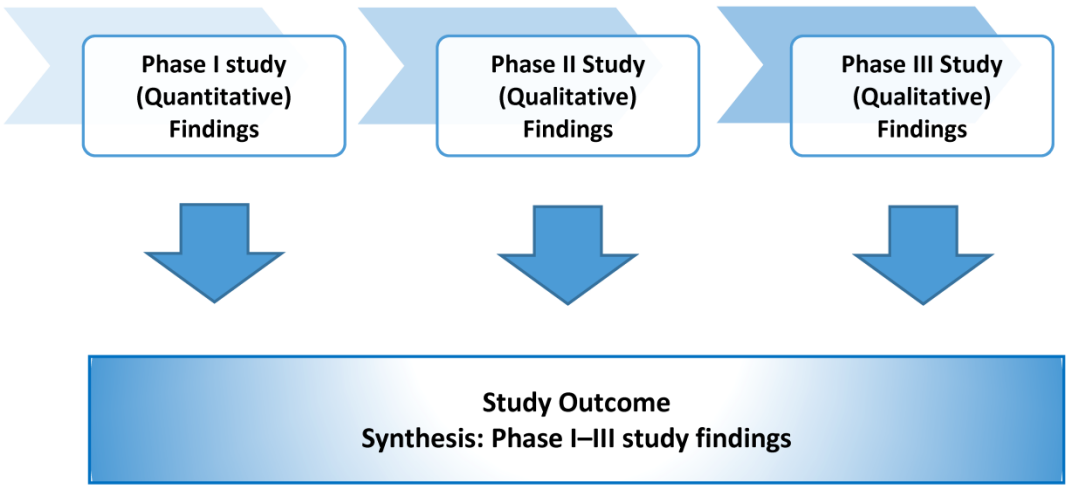

Figure 1. Sequential mixed methods research design

The phase I quantitative study used practice-based research methodology of clinical data mining (Epstein, 2001; Dodd et al., 2012). CDM provides multidisciplinary allied health practitioners a pragmatic strategy (Joubert & Epstein, 2005) to generate valuable research knowledge from existing raw qualitative and/or quantitative data when accurately retrieved and transformed into reliable and valid form that is then analysed and used to understand clinical practice phenomena and inform healthcare decision making (Epstein, 2010). This methodology has been successfully used in health science research (Lalayants et al, 2012). Quantitative data were yielded from the medical records of 74 patients meeting the study inclusion criteria to gain insight into the clinical and sociodemographic profile of parents receiving hospital-based noncurative cancer treatment diagnosed with IESC who are parenting one or more children aged 18 years and younger—focusing on their parenting-related issues and parenting-focused service responses. Using this retrospective strategy avoided the unnecessary disturbance of patients undergoing palliative-stage healthcare treatment and possible high participant attrition rates due to fluctuating health or death. Longitudinal data over sensitive and/or complex periods of patients' lives (including the final weeks of their life) was also able to be readily obtained. Important information regarding which patients who met inclusion criteria did not receive parenting supportive care from their healthcare team during the IESC treatment phase can shed light on potential gaps in service provision or other associated factors. The benefit of collecting historically reported parenting supportive care interventions also means that the research process has not influenced any aspect of supportive care service delivery.

The phase II qualitative study involved interviewing multidisciplinary hospital health professionals in a focus group forum to obtain their perspective of the parenting-focused supportive care needs of this patient subgroup and hospital-based parenting supportive care service responses. A cross-sectional qualitative design was selected for this study to capture in-depth and rich data elicited from health professionals' experience not currently understood or attainable through

quantitative methods. The focus group method was purposively selected due to its evidenced success in parental palliative care research investigating optimal healthcare delivery (Arber et al., 2018; Punziano, Piredda, Mastroianni, Fiorelli & Marinis 2017; Turner et al., 2007b). Focus groups provide added benefits to individual interviews, with the naturalistic approach of using common relational methods of communication (Wilkinson, Bailey, Aldridge & Roberts, 1999), the synergy created between group members (Wilkinson, 1998), and its function of inspiring participants to reveal views and beliefs that might not have otherwise arisen in individual interviews. To address possible participation issues that could have arisen on the day (e.g., unforeseen clinical emergencies) or prior to the focus group being conducted (e.g., personal sensitivities), individual interviews were offered.

The phase III qualitative study utilised semi-structured in-depth individual interviews with patients and their nominated co-parent (where present). A cross-sectional, exploratory qualitative methodology was chosen as little is known about the parenting needs and experiences of hospital-based parenting supportive care services from the perspectives of parents facing IESC with young families. This approach and the flexibility offered by semi-structured interviews with open-ended questions, enables the interviewer to respond respectfully to each participant (Hogden et al., 2012) and to thoughtfully navigate sensitive topics raised. It has been employed extensively with healthcare consumers in the relatively under researched field of parental cancer (Dencker et al., 2019; O'Neill et al., 2018; Park, Check et al., 2017) and palliative care (Broom & Cavenagh, 2011; Collins, McLachlan & Philip, 2018).

Descriptive statistics (VanderStoep et al., 2008) were used to interpret quantitative data. All qualitative data were analysed using thematic analysis (Braun & Clarke, 2006; 2013).

Research environment

The study was undertaken at the Western Health (WH) Melbourne, Victoria, Australia. Western Health provides a comprehensive range of healthcare services across multiple sites in the western metropolitan area of Melbourne, serving a culturally, socially and economically diverse population close to 900,000 people; cancer being a significant population health issue in the region (WH, 2019). Healthcare services managed by WH range from three acute tertiary public hospitals providing emergency medicine, intensive care, medical and surgical services, including the Sunshine Hospital Radiation Therapy Centre—a joint initiative between WH and the Peter MacCallum Cancer Centre—through to subacute and specialist ambulatory care services, and community-based services. Patients diagnosed with IESC who access the oncology and palliative healthcare services at WH may also access healthcare treatment from other local private and public hospitals and community-based services. This research study was hosted by the WH Cancer Services and Palliative Care with significant support from the WH Social Work Department, a department dedicated to providing psychosocial supportive care service to WH patients and their families, including adult patients diagnosed with IESC. WH has long-standing collaborative academic partnerships with The University of Melbourne and other health providers and academic institutions. The intention of this study was premised on investigating the research questions and feeding the results back into practice (Epstein, 2001; Dodd et al., 2012).

Research participants

All participants recruited for the study—patients (parents diagnosed with IESC), co-parents and multidisciplinary health professionals—were directly associated with WH as a healthcare consumer (inpatient or outpatient) or hospital-based practitioner.

For the phase I study, participants recruited comprised adult patients who had received an IESC diagnosis and parenting one or more children aged 18 years and younger and had been a recipient of WH noncurative cancer treatment—with qualifying evidence clearly documented in their respective hospital medical records. Patients with any type of cancer type and sociodemographic characteristics were included. Given participants recruited were not directly involved in any form of interviewing as the study entirely entailed the retrospective data mining of patient medical records, only patients identified as meeting the inclusion criteria who had died prior, during or after the data collection period were included. It was anticipated that by having broad participant inclusion criterion it would enable rich data to be collected from a clinically and sociodemographically diverse patient group, including those experiencing mental health conditions, family violence and death, not previously explored within the context of hospital-based palliative-stage parental cancer intervention research.

The multidisciplinary health professionals recruited for the phase II study included medical, nursing and allied health professionals working across the inpatient and outpatient cancer and palliative care services. All clinical areas offered similar models of multidisciplinary care comprising doctors, nurses and an allied health team. Two key differences were noted: a) the referral system varied across individual disciplines, with only allied health disciplines reporting use of a 'blanket referral' system whereby inpatients with IESC are systematically offered a supportive care service and b) a Specialist Cancer Care Nurse was not employed in all cancer streams. Patients receiving noncurative cancer and/or palliative care treatment at WH have access to inpatient and/or outpatient healthcare services. Inpatient treatments were provided on general wards as well as specialist cancer and palliative care. Outpatient treatment took place in a clinic setting and/or a day unit such as the Day Oncology Unit. The inclusion of participants from both the inpatient and outpatient hospital settings promoted a more diverse sample with a broader range of clinical experiences than a single setting could offer.

Patients and co-parents selected for the phase III study comprised patients who had been identified by their WH healthcare team as having IESC and parenting one or more minor-aged children. Patients included in the study were not a subset of participants recruited to the phase I study. To promote the inclusion of Australian non-English speaking parents in the study, full provisions were made to have an onsite interpreter available for all aspects of the interview process—from the initial point of the study invitation and consent, to the end of the interview. Aside from patients who are too unwell or cognitively impaired to give informed consent, all patients of varied clinical (e.g., cancer type and time since IESC diagnosis) and sociodemographic background (e.g., age, sex, parenting status: single and co-parenting and country of birth) who were interested in participating in the study were considered. The aim of the study was to capture the viewpoints of a relatively heterogeneous group of patients and co-parents.

Research methodology summary

The research questions, study design, participants and outputs produced are presented below (Table 1). Further details of data collection and analysis are contained within each corresponding chapter.

Table 1. Research project overview

Research questions	Method	Connectivity of studies	Participants	Thesis chapters
RQ What are the parenting supportive care services offered as part of routine hospital-based palliative cancer care to adult patients raising minor-aged children?				
RQA What documented parenting supportive care is provided to adult hospital patients with IESC who are parenting children up to 18 years old and receiving palliative care treatment?	**Quantitative** Data collection: Clinical data mining Data source: Patient medical records Data analysis: Descriptive statistics	Findings inform research questions - phase II & III studies	Total patients *N* = 74	**Chapter 3** Comprises an Author's Original Manuscript: Steiner, V. Joubert, L. Shlonsky, A. & Dabscheck, A. (n.p.). Parenting in the palliative stage: A clinical data mining study of hospital-based supportive care.
RQB What are multidisciplinary HP perspectives on the parenting experiences and support needs of patients (and co-parents) diagnosed with IESC and factors influencing optimal parenting supportive care?	**Qualitative** Data collection: Semi-structured in-depth (1 focus group & 2 individual interviews) Data source: Hospital-based multidisciplinary health professionals Data analysis: Thematic analysis	Findings inform research questions - phase III study	Total multidisciplinary health professionals *N* = 12	**Chapter 4** Comprises an Author's Original Manuscript: Steiner, V. Shlonsky, A. Joubert, L. & Morris, A. (n.p.). Hospital parenting support for adults with incurable end-stage cancer: Multidisciplinary health professional perspectives.

Research questions	Method	Connectivity of studies	Participants	Thesis chapters
RQC What are the perspectives of patients diagnosed with IESC and their families of hospital-based parenting related supportive care, their experiences and supportive care needs, and what factors facilitate and hinder optimal parenting supportive care?	**Qualitative** Data collection: Semi-structured in-depth Data source: Parents (9 interviews: 8 individual; 1 joint) Data analysis: Thematic analysis		Total parents *N* = 12 Patients *n* = 8 Co-parents *n* = 4	**Chapter 5** Comprises the publication: Steiner, V. Joubert, L. Shlonsky, A. & Hocking, A. (2020). Australian hospital-based parenting support for adults with incurable end-stage cancer: Parent perspectives. *Journal of Evidence-Based Social Work, 17*(2), 172–190. doi:10.1080/26408066.2019.1705957
	Mixed methods Data source: Phase I–III study findings Data integration: Narrative synthesis		As above (PI-III studies)	**Chapter 6**

CHAPTER 3

Phase I study: Hospital parenting supportive care practice

Overview

Chapter 3 examines the documented parenting and psychosocial needs of patients and their families facing incurable end-stage cancer that were made visible to the multidisciplinary health professional team and the supportive care service response delivered as part of routine hospital-based multidisciplinary healthcare.

This chapter comprises the Author's Original Manuscript of an article under review by Taylor & Francis in *Social Work in Health Care* (American spelling; references included):

Steiner, V. Joubert, L. Shlonsky, A. & Dabscheck, A. (n.p.). Parenting in the palliative stage: A clinical data-mining study of hospital-based supportive care.

Author	(%)	Contribution
Vera Steiner	65	Conception and design, analysis and interpretation of data and drafting of manuscript
Lynette Joubert	15	Conception and design, interpretation of data and critical review of manuscript
Aron Shlonsky	15	Conception and design, interpretation of data and critical review of manuscript
Adrian Dabscheck	5	Critical review of manuscript

Abstract

The objectives are to explore the supportive care provided to adult hospital patients with incurable end-stage cancer (IESC) for parenting-related issues. Seventy-four consecutively identified patient cases were retrospectively data-mined for clinical, socio-demographic, and psychosocial quantitative and qualitative information. Descriptive analysis revealed trends in multidisciplinary parenting-related supportive care practice. Key findings focus on patient demographics, the psychosocial context of parenting-related support, and access to—and delivery of—support over the course of patients' IESC journey. The findings provide new insights into what parenting supportive care is occurring as part of routine hospital health care practice, informative for future research.

Keywords*:* data-mining, health professional, palliative care, parental cancer, parenting, psychosocial intervention

Introduction

Cancer is among the highest causes of death in Australia and worldwide for both men and women (Australian Institute of Health & Welfare [AIHW], 2019; World Health Organization [WHO], 2015). International epidemiological data on the prevalence of advanced parental cancer is sparse (Zaider, Salley, Terry, & Davidovits, 2015) as cancer staging and parental status data is not collected by national Cancer Registries. In 2015 the United States cancer statistics showed that 338,840 adults of child rearing age (20-74 years) died from cancer in 2015 (U.S. Cancer Statistics Working Group, 2018). Estimations from projected 2019 Australian cancer data indicates that thousands of parents with dependent children will be among those who die from cancer this year (AIHW, 2019).

Parenting during the incurable end-stage cancer (IESC) phase is challenging given the myriad of competing illness-related and parenting demands. Parents often adapt with resiliency to the major change in life circumstance that a cancer diagnosis brings (Helseth & Ulfsaet, 2005), however parents with a poor prognosis face higher risk of psychosocial distress (Nilsson et al., 2009), as do their co-parents and children (Aamotsmo & Bugge, 2014; Phillips & Lewis, 2015). Multifactorial psychosocial stressors unique to the palliative phase are experienced and parenting concerns are at the fore (Park, et al., 2016). Parents' well-being has a ripple effect on the family unit—affecting parenting capacity, parent-child communication, family functioning (Zaider et al., 2015). Being a parent of dependent children can affect patients' health care treatment decision-making with parents more likely to opt for more aggressive treatments with very limited benefits and taxing side-effects to extend time with their children (Check, et al., 2017; Nilsson et al., 2009).

The full dimension of hospital-based supportive care for parenting-related issues is yet to be comprehensively examined and understood. Historically, related parental cancer research studies have predominantly recruited middle-class married mothers with breast cancer (Semple & McCance, 2010) and those with earlier stage cancers. Under-represented groups include fathers (O'Neill, McCaughan, Semple, & Ryan, 2013), single-

parents (Behar & Lewis, 2015; Nadimi & Currow, 2008), parents from a culturally and linguistically diverse background (CALD) (Davey, Kissil, Lynch, Harmon, & Hodgson, 2013), and those with a lower socio-economic status (Visser, Huizinga, Hoekstra, van der Graaf, & Hoekstra-Weebers, 2006). Psychosocial supportive care is endorsed worldwide as an essential element of quality palliative & oncology health care (Institute of Medicine, 2013; National Breast Cancer Centre & National Cancer Control Initiative; 2003; National Institute for Health & Care Excellence, 2004), however international empirical and research evidence indicates parents' supportive care needs are infrequently addressed in the primary health care setting as part of routine psychosocial health care practice (Helseth & Ulfsaet, 2005; Turner et al., 2007).

This study aims to answer the exploratory question: What documented parenting supportive care is provided to adult hospital patients with IESC who are parenting children up to 18 years old and receiving palliative care treatment? Focusing on the parenting perspectives of psychosocial supportive care, findings will potentially contribute to the evidence base by providing a description of patient demographics, the pressing parenting and psychosocial concerns that come to the attention of the multidisciplinary team (MDT), and the trends in parenting supportive care response. Ultimately, the intended outcome is to assist in the development of a parenting-inclusive psychosocial supportive care model of practice suitable for fast-paced hospital settings where interventions need to be brief.

Materials and methods

This study utilized an exploratory design underpinned by a practice-based research approach (Dodd & Epstein, 2012). Clinical data-mining (CDM) was employed to collect quantitative and qualitative data created during routine clinical practice (Epstein, 2001). Hospital-based health professionals (HPs) regularly generate large quantities of patient data including clinical, socio-demographic, and psychosocial information. CDM enabled rich baseline data to be retrospectively collected without unnecessarily engaging with palliative patients; high attrition due to participants' deteriorating health and death was avoided. Study findings reported will contribute to a larger dataset

exploring parenting-related supportive care for hospital patients diagnosed with IESC and parenting dependent children.

Participants and setting

Patients from a public tertiary hospital in Melbourne Victoria, Australia were recruited by purposive sampling using two merged patient referral lists comprising 2144 referrals recorded between the dates of 1 September 2013 to 31 December 2015. Electronic patient medical records across four patient management data systems were sequentially screened to identify 74 participants who met study inclusion criteria: adult patient, primary diagnosis IESC (any type), parenting one or more children aged up to 18 years old at the time of IESC diagnosis, and received noncurative hospital treatment. Inpatient and outpatient palliative and cancer treatment services are provided free of charge to patients under Australia's universal health care system. No targeted parenting programs were operating during the period of data collection.

Data collection and analysis

Participants' electronic medical records were retrospectively data-mined using a CDM Audit Tool developed by the non-Western Health (WH) researcher (V.S.) and reviewed by two external expert researchers (L.J., A.S.) and two WH clinicians (A.M., J.V.). The tool captured quantitative and qualitative data including clinical and socio-demographic information, and psychosocial and parenting supportive care provision. The tool remained dynamic during data collection to allow for the addition or modification of relevant psychosocial items. De-identified data were collected using a custom-built database. Quantitative data were transferred to data analytic software IBM SPSS Statistics Version 24 for descriptive and inferential statistical analysis. Qualitative data were reviewed thematically to aid the descriptive analysis process. Data collection occurred between August 2016 and December 2017. Ethical approval was granted by the Human Research Ethics Committee at WH Melbourne [EC00235]. Descriptive analysis was undertaken to define the sample. Data were distilled, first using theory to guide a selection of bivariate comparisons, followed by statistical tests to guide data reduction.

For categorical-by-categorical variables the nonparametric Fisher's Exact Test stratified to the 2X2 level was employed.

Results

Population

Seventy-four patients met the inclusion criteria of the 2144 patient referrals reviewed, they comprised 19% of the 389 patients identified with a primary diagnosis of cancer who accessed inpatient and/or outpatient palliative care treatment at WH from 1 September 2013 to 31 December 2015. Clinical and socio-demographic characteristics of the patients revealed a diverse population (Table 1). Ethnicity data were not reliably presented in the files; no patients of Aboriginal or Torres Strait Islander origin were identified. Patients comprised 39% males and 61% females age range: 27–75 years (*M* = 47 years); 65% were younger than 50 years old at the time of IESC diagnosis. Collectively, patients were parenting 130 children (0–18) years old (number per family: 1—5; *M* = 1.8; youngest child: *M* = 10 years and oldest: *M* = 13 years; 84% 1–2 children per family unit). Timing from initial cancer diagnosis to IESC diagnosis varied significantly (range: 1–170 months; *Mdn*: 1 month; *M* = 19.5 months). Over half of the patients (54%, 40) received their IESC diagnosis within one month of their initial cancer diagnosis (58% > 50 years old: 53% female; 50% born overseas; 12% were single-parenting). Collectively, patients made 1471 hospital visits (range: 1–120; *M* = 20). Time from patients' first documented hospital visit to their last visit during the data collection period (*M* = 8 months). During the IESC phase 87% (64) of patients were linked with informal supports including family and friends and 92% (68) with formal community support services; 78% (58) had both informal and formal support networks. Data detailing when supports were accessed during the IESC journey was not available.

Table 1. Clinical and sociodemographic characteristics of patients

N = 74			
Time: Initial cancer dx to IESC dx (months)	***n* (%)**	**Primary reason: hospital visits***	***n* (%)**
≤ 1	40 (54)	Cancer treatment	1252 (85)
2-12	6 (8)	Uncontrolled symptoms	145 (10)
13-24	7 (10)	Other	49 (3)
25-36	7 (10)	End-of-life care	25 (2)
37-170	14 (18)		
Destination: last hospital visit		**Treatment: Study site and other hospitals**	
Home	48 (65)	Yes	74 (100)
Died in hospital	24 (33)		
Other	2 (2)		
No. patients by child age (group)		**Place of usual residence**	
0–11 years only	27 (36)	West Melbourne metropolitan	70 (95)
12–18 years only	31 (42)	Other	4 (5)
0–18 years (both)	16 (22)		
Parental relationship status		**Parental relationship type**	
Married/de facto	53 (72)	Opposite sex	74 (100)
Separated/divorced/single	21 (28)		
Changed post IESC diagnosis	4 (5)		
Family structure		**Parenting status**	
Intact couple with children	42 (57)	Co-parenting: partner or ex-partner	55 (74)
Other	32 (43)	Single-parenting	19 (26)
Changed post IESC diagnosis	4 (5)	*Changed post IESC diagnosis*	6 (8)
Country of birth		**Primary language**	
Australia	39 (53)	English	59 (80)
Overseas	34 (46)	Other	15 (20)
Not stated	1 (1)		
Employment status		**Primary income source**	
Employed	42 (57)	Wage	36 (49)
Unemployed	21 (28)	Government Centrelink payment	22 (30)
Not stated	11 (15)	No income	2 (3)
		Not stated	13 (17)
		Changed post IESC diagnosis	40 (54)
Religion		**Occupation****	
Christianity	37 (50)	Technician, trade worker	19 (26)
Buddhism	7 (9)	Admin, sales, service worker	11 (15)
Other	4 (6)	Manager, professional	8 (11)
No religion	19 (26)	Not stated	36 (48)
Not stated	7 (9)		

Abbreviations: Dx, diagnosis; No., number; other (family structure), other: blended family, couple without children residing in same home, kinship, separated couple together with children, single parent with children, single parent without children in same home children.
Note: *1 hospital visit comprised either one inpatient hospital stay or 1 day of outpatient appointments. ** Australian and New Zealand Standard Classification of Occupations (ANZSCO)

Parenting support provision: psychosocial supportive care context

To simplify analysis similar types of psychosocial supportive care from the original list of 30 individual variables were aggregated into 13 clusters (Table 2). Most patients (93%, 69) were documented as receiving attention for a range of psychosocial concerns arising during the IESC phase; 82% received support for a minimum of four types of issues. Following practical support, parenting was among the top issues for which patients received support.

Table 2. Psychosocial supportive care provision by issue type (clustered) N = 74

Psychosocial issue (clustered)	Details (examples)	Patients *n* (%)
Practical	ADLs, service information & coordination, respite, social support, transport, travel (patient & co-parent)	65 (88)
Parenting	Child physical, psychological, emotional, social, & spiritual well-being (including child at-risk) & parenting-related distress, roles & responsibilities (patient & co-parent)	57 (77)
Emotional & psychological distress	Adjustment, bereavement, loss & grief: historical & current (patient)	57 (77)
Finance, work, legal	Employment changes, financial strain & income loss, government social benefit application, legal: advanced care directive, family law, power of attorney, visas, Will (patient & co-parent)	57 (77)
Co-parent	Emotional & psychological distress: including anticipatory grief & loss, family conflict, physical burden, young carer (co-parent)	46 (62)
End of life care	Health care planning, funeral assistance (family)	32 (43)
Mental health disorder &/or trauma	Past & current (patient)	26 (35)
Family	Adult behavior, cancer communication, gambling, parental relationship: partner, ex-partner (family)	25 (34)
Bereavement	Two weeks prior/post death: anticipatory grief, grief, & loss (children, co-parent, ex-partner, ext family, & significant others)	23 (31)
Other health	Other health: cognitive, genetic, health care consumer, sexual, & substance misuse (patient)	21 (28)
Housing	Homelessness: home relocation: home physically unsuitable, & family violence (patient)	14 (19)
Spiritual & religious	Distress: volunteer hospital visitors proselytizing, exploring religions, fear of children/co-parent losing religious faith, last rites, & referral to pastoral care (patient)	13 (18)
Family conflict & violence	Family conflict: patient's parents/partner, patient/patient's parent Family violence: patient/partner, patient/ex-partner, patient's parents/ ex-partner, between patient's parents (family)	9 (12)
No issues		5 (7)

Abbreviations: ADLs, activities of daily living; EOLC, end-of-life care; ext family, extended family members; others, significant others.

Parenting support interventions (by issue type)

Parenting supportive care was clustered into 14 categories classified by parenting issue type. Fifty-seven (77%) of patients had at least one type of parenting issue recorded; 39

(53%) had a minimum of three (range: 1–11 types; *M* = 4) throughout their IESC journey. Table 3 lists the individual types of parenting support provided and the MDT involved in service provision. Social work was the sole profession to provide support across the full breadth of parenting issues. Qualitative data demonstrated that when parenting support was provided to a patient it was not a one-off intervention but occurred at various intervals during the IESC phase (IESC phase range: 1—23 months; *M* = 5 months) except for cases where parents had very few hospital visits.

Table 3. Parenting supportive care: prevalence by issue type and health professional provider

Parenting issues (***N* = 74**)	**Patients** ***n* (%)**	**Health professional provider** *HPs listed in descending order of involvement*
Child well-being: behavioral, emotional, psychological, social	47 (64)	SW, Dr, Nurse, CPsych, PCS
Enhancing quality time	28 (38)	SW, Dr, CPsych, OT, Nurse, PT
Talking to children: IESC	27 (36)	SW, CPsych, Dr, PCS
Role & responsibilities	26 (35)	SW, Dr, OT, Nurse, CPsych, PT
Parental sadness, guilt, worry	26 (35)	SW, CPsych, Nurse, Dr, OT
Future planning	17 (23)	SW, Dr, CPsych, Nurse
Child care	16 (22)	SW, Dr, Nurse
Referral: child counselling service	13 (18)	SW, Dr
Memory making	11 (15)	SW, Dr, Nurse, OT, PT
Talking to children: death	10 (14)	SW, CPsych, Dr, Nurse, OT
Schooling	9 (12)	SW, Dr, Nurse
Coordinating children's hospital visits	8 (11)	SW, Nurse
Child with disability	7 (9)	Dr, SW, OT, CPsych
Parenting: other	3 (4)	SW, Dr

Abbreviations: CPsych, Clinical Psychology; Dr, Doctor (including non-specialists and specialists: oncology, palliative care and psychiatry); OT, Occupational Therapy; PCS, Pastoral Care Service; PT, Physiotherapy; SW, Social Work.

Parenting support provision: patient profile

Patients whose parenting issues came to the attention of the health care staff comprised: 21 males and 36 females (cancer type: 26% breast, 26% GIT, 22% lung, and 26% other; range: 34–75 years old, number of children [0–18] years old ranged: 1–5, *M* = 1.9; 30% single-parenting; 49% born overseas; 90% had access to external formal support

services; and, 88% had informal supports in situ). Seventeen (23%) patients received no parenting-related interventions: 8 males and 9 females (cancer type: 24% breast, 12% GIT, 35% lung, 29% other; range: 27–70 years number of children (0–18) years old ranged: 1–3, *M* = 1.5; 12% single-parenting; 35% born overseas; 100% were linked with external formal support services including social workers and psychology from other hospitals; and 82% had informal supports).

Parenting support interventions (by issue type): clinical & socio-demographic factors

Fisher's Exact testing indicated there were no clinical or socio-demographic factors, inclusive of informal and formal supports, related to whether patients received parenting supportive care or not. Patients who accessed hospital-based treatment for the full IESC phase (IESC diagnosis to end-of-life) did not receive increased support for parenting concerns (*p* .780).

Relationships between clinical and socio-demographic factors and the individual types of parenting supportive care provided were explored using Fisher's Exact Testing. Cancer type had no association to any particular type of parenting support however timing of the IESC diagnosis did. Parents diagnosed with IESC within one month of their initial cancer diagnosis were more likely to receive assistance with child care matters (32.5%, 13; 8.8%, 3; *p* .022) and parents whose IESC journey was reviewed from IESC diagnosis to end-of-life did not receive increased assistance for any individual parenting concerns than parents whose data were collected for shorter periods.

Socio-demographic factors, children's age (by age group) and number of children (0–18 years old), were linked to higher support across a broad spectrum of parenting issues. Patients parenting at least one child under 12 years old received proportionally more support focused on quality time (51.2%, 22; 19.4%, 6; *p* .007), parental role and responsibilities (46.5%, 20; 19.4%, 6; *p* .025), child care (30.2%, 13; 9.7%, 3; p .046), and memory making (23.3%, 10; 3.2%, 1; *p* .020) compared to those raising only teenaged children. Raising three or more children aged (0–18) years was significantly related to increased interventions focused on addressing parental sadness, guilt, and worry

(66.7%, 8; 29%, 18; *p* .020), child care (50%, 6; 16.1%, 10; *p* .017), and memory making issues (41.7%, 5; 9.7%, 6; *p* .013). Patient age and sex had few significant associations; patients under 50 years old received more child care related interventions (31%, 15; 3.8%, 1; *p* .007) and females had increased support with future planning issues (31.1%, 14; 10.3%, 3; *p* .049). Single-parenting patients (26%, 19) had a higher proportion of supportive care dedicated to future planning (42.1%, 8; 16.4%, 9; *p* .030) and talking to children about IESC (57.9%, 11; 29.1%, 16; *p* .031) compared to their counterparts. Patients who were reported as having a religion had increased support for parenting role and responsibility based issues (57.9%, 11; 27.1%, 13; *p* .025) than patients who were reported as having no religion. No specific socio-demographic factors were related to interventions focused on child well-being, parenting a child with a disability, coordinating children's hospital visits, referral to child counseling services, schooling, and talking to children about death, indicating parents were universally provided these interventions irrespective of any particular socio-demographic factor.

Parenting support interventions (by issue type): psychosocial factors

Investigations utilizing Fisher's Exact testing revealed patients who received supportive care for distress and family-related issues received proportionately greater assistance for a large range of parenting issues compared to their cohorts (Figures 1–2).

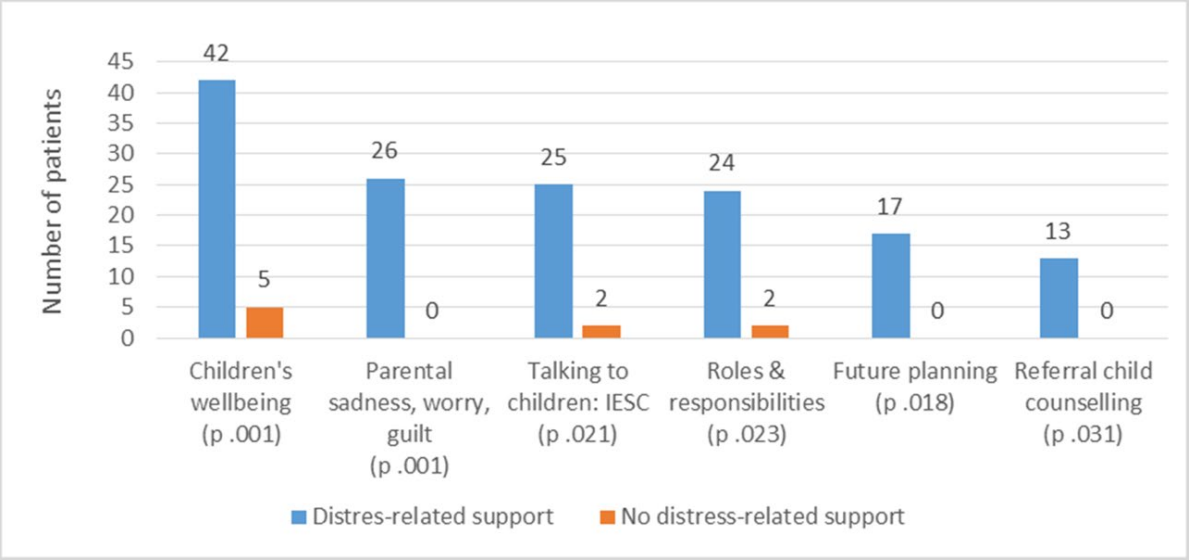

Figure 1. Significant relationships: distress issues (patient) & individual parenting issues

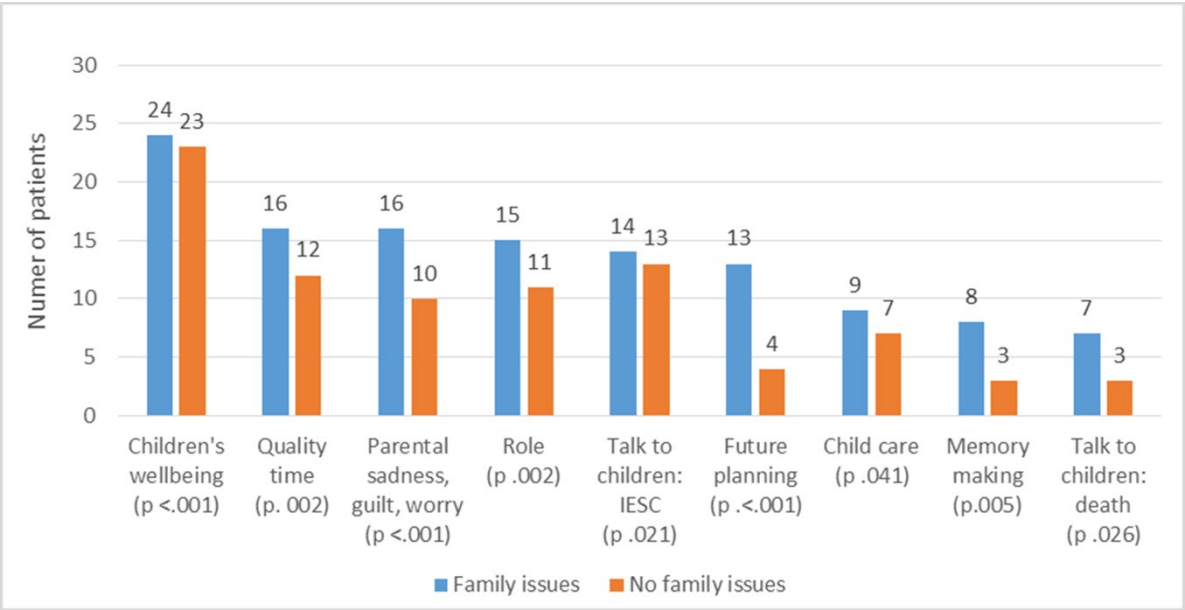

Figure 2. Significant relationships: family issues & individual parenting issues

In families where co-parent support was accessed, an increase in practical support for child care (30.4%, 14; 7.1%, 2; *p* .021) and coordinating children's hospital visits (17.4%, 8; 0%, 0; *p* .021) was observed. Patients who received support for end-of-life issues—bereavement and EOLC—had proportionately increased interventions across three parenting issues. Bereavement support was associated with increased support for children's well-being (91.3%, 21; 51.0%, 26; *p* <.001), quality time (56.6%, 13; 29.4%, 15; *p* .038), and memory making (30.4%, 7; 7.8%, 4; *p* .029). EOLC was associated with increased interventions relating to enhancing quality time with the children (53.1%, 17; 26.2%, 11; *p* .029).

Parenting support provision: relationship to other psychosocial interventions

Analysis of the significant relationships between parenting and other psychosocial support interventions (by issue type) was conducted using Fisher's Exact testing. Results revealed patients who received parenting support accessed proportionately more interventions across multiple psychosocial issues including bereavement, co-parent, distress, family, finance/work/legal, practical, and mental health disorder and/or trauma (Table 4). A similar trend was noted for patients who received distress-related,

co-parent support, or family support; they were received proportionately increased parenting support, and assistance with other psychosocial matters.

Table 4. Relationships between parenting and psychosocial interventions (by issue type)

		Psychosocial issues											
***N* = 74**		**Parenting**			**Distress (patient)**			**Co-parent**			**Family**		
		Yes *n* (%)	**No *n* (%)**	***p* value**	**Yes *n* (%)**	**No *n* (%)**	***p* value**	**Yes *n* (%)**	**No *n* (%)**	***p* value**	**Yes *n* (%)**	**No *n* (%)**	***p* value**
Psychosocial issues	*n*												
Bereavement	23	22 (39)	1 (6)	.015**	20 (35)	3 (18)	.237	5 (18)	18 (39)	.072	11 (44)	12 (25)	.113
Co-parent	46	42 (74)	4 (24)	<.001***	39 (68)	7 (41)	.051	-	-	-	16 (64)	30 (61)	1
Distress (patient)	57	50 (88)	7 (42)	<.001***	-	-	-	18 (64)	39 (85)	.051	25 (100)	32 (65)	<.001***
End-of-life	32	28 (49)	4 (24)	.094	28 (49)	8 (47)	1	31 (67)	5 (18)	<.001***	12 (48)	20 (41)	.220
Family	25	24 (42)	1 (6)	.007**	25 (44)	0 (0)	<.001***	16 (35)	9 (32)	1	-	-	-
Family violence & conflict	9	9 (16)	0 (0)	.107	9 (16)	0 (0)	.107	6 (13)	3 (11)	1	36 (9)	0 (0)	<.001***
Finance, work, & legal	57	49 (86)	8 (47)	.002**	51 (90)	6 (36)	<.001***	39 (85)	18 (64)	.051	23 (92)	34 (69)	.040*
Housing	14	13 (23)	1 (6)	.166	14 (25)	0 (0)	.030*	11 (24)	3 (11)	.225	9 (36)	5 (10)	.012*
Parenting	57	-	-	-	50 (88)	7 (41)	<.001***	40 (87)	15 (54)	.002**	24 (96)	31 (63)	.002**
Practical	65	56 (98)	9 (53)	<.001***	54 (95)	11 (65)	.004**	46 (100)	19 (68)	<.001***	24 (96)	41 (84)	.258
MH disorder &/or trauma	26	26 (46)	0 (0)	<.001***	26 (46)	0 (0)	<.001***	18 (39)	8 (29)	.454	17 (68)	9 (18)	<.001***
Spiritual &/or religious	13	12 (21)	1 (6)	.275	9 (16)	4 (24)	.480	11 (24)	2 (7)	.113	5 (20)	8 (16)	.752

Abbreviations: distress, emotional and psychological distress
Note. *$p < .05$, **$p < .01$, ***$p < .001$ (Fishers Exact Test)

Psychosocial services declined

Few patients (5%, 4) declined an offer for psychosocial support during the IESC phase (75% male and partnered, 25 % female and unpartnered; age range: 48–51 years, *M* = 48.8); prior to declining the support offer all had received hospital-based psychosocial support and 75% had accessed parenting supportive care; 50% accessed supportive care four months later. Qualitative data revealed three aspects underpinning patients' rationale for their decisions: strong family support (partnered male patients), exhaustion (unpartnered female patient), and prioritization of palliative treatment addressing physical symptoms such as pain and functional decline (all). Thirty five patients (57%) declined offers of linkage to external supportive care services during the IESC phase (male 43%, female 57%; age range: 34–75 years, *M* = 47.9); 89% of these patients were documented as linked with external supportive care services; there was insufficient data to confirm if patients were already linked with external services when support offers were declined.

Support service delivery

Following the diagnosis of IESC, parenting status was first identified and communicated in patients' medical records by a wide range of HPs. In descending order of involvement, they were: medical (65%, 49), social work (14%, 10), nurses (14%, 10), clinical psychology (3%, 2), and occupational therapy/physiotherapy (4%, 3). Children's specific ages were not routinely reported with phrases such as 'young children' or 'school-aged children' often used.

Patient referral pathways were unable to be defined due to inconsistent reporting of referral data. Referral sources—where documented—included patients, patients' caregivers and family members, individual HPs, oncology and palliative care MDTs, and HPs including social workers working in external agencies. Few patients received psychosocial care distress screening: 11% (8) patients received one screen, of which 38% (3) received a second screen.

Psychosocial supportive care was delivered using an interdisciplinary approach. Ten HP disciplines spanning the medical, nursing, and allied health professions provided psychosocial supportive care to patients and their families. Social work were documented as providing psychosocial support to the most patients (86%, 64), followed by doctors (58%, 43), occupational therapy (50%, 37), nursing (45%, 33), clinical psychology and neuropsychology (28%, 21), physiotherapy (24%, 18), pastoral care (12%, 9), and dietetics (4%, 3). Social work was the only discipline to provide child-inclusive counseling (8%, 6).

Discussion

Parenting supportive care service provision

This exploratory study offers a nuanced view of what parenting supportive care services were documented and delivered to a diverse cohort of patients and their co-parents while they accessed brief hospital-based palliative cancer treatment—a practice-based perspective not captured by previous studies. Parenting was a prominent, serious and pressing psychosocial concerns that came to the attention of HPs. Despite the high burden of parenting concerns evidenced, one quarter of patients did not access parenting support, reflecting results from a population-based study including parents with earlier stage cancer (Ernst et al., 2013). It is surmised this is likely an underestimation of the true figure given parenting status was not systematically recorded in patients' medical notes therefore potentially excluding parents otherwise eligible for study inclusion. Other reasons for this shortfall likely point to various patient, HP, and/or organization-related factors (Dencker, Rix, Bøge, & Tjørnhøj-Tømsen, 2017; Dilworth, Higgins, Parker, Kelly, & Turner, 2014; Inhestern, Haller, Wlodarczyk, & Bergelt, 2016; Turner et al., 2007). Qualitative studies exploring patients' preferences for parenting supportive care provision—whether it is hospital-based support and/or community-based and the factors that facilitate and impede optimal hospital-based parenting support—are needed to better understand how access to—and delivery of—interventions can support patients at this critical stage of life and parenting. Additional research is needed to examine how hospital-based parenting

support is instigated as this was not discernible from the data recorded in patients' medical notes. Were parenting issues raised by the patient or co-parent, a hospital-based HP, and/or via a referral from an external agency? Parents with IESC (Bugge, Helseth, & Darbyshire, 2009) and those with no reported health concerns often find it difficult to initiate parenting support for fear of being criticized or harshly judged stemming from their lack of confidence (Tucci, Mitchell, & Goddard, 2004).

Data-mining patients' medical records reported over time confirmed that parenting-related supportive care was delivered at various intervals along patients' IESC journeys, at both medical and psychosocial points of crisis and distress. All patients were linked with informal supports, with many also linked external support services suggesting that hospital-based parenting-focused supportive care may serve to supplement external supportive care along the disease trajectory (Russell & Rauch, 2012). Service provision was driven by an MDT approach and occurred as part of routine psychosocial supportive care practice within the inpatient and outpatient settings. Overall, the social work profession proved to be central to practice, an anticipated result given their established clinical expertise and skill working with diverse patient populations diagnosed with cancer experiencing complex psychosocial stressors and family-focused approach to supportive care (Christ, Messner, & Behar, 2015). Interventions addressed multidimensional psychosocial and parenting stressors that were past-, present-, and future-based. The confronting stressors disclosed indicated patients' and co-parents' willingness to expose their parenting vulnerabilities with a range of HPs, their receptiveness to receiving support, and the capacity of HPs to create a conducive environment for disclosure during brief hospital visits.

This study offers an overview of the various factors related to parenting supportive care provision. Psychosocial factors alone were associated with whether patients and co-parents accessed parenting supportive care or not. In contrast, clinical, socio-demographic, and psychosocial factors were all related to the type of parenting-related support provided. There are many plausible contributing factors for these trends including, but not limited to: comprehensive family-focused psychosocial assessments revealed parenting concerns, rapport was established through psychosocial

interventions first before patients and co-parents were comfortable discussing parenting concerns, and clinical or socio-demographic factors did not drive supportive care referrals. Disease progression and familial-based factors had a stronger influence on the types of parenting support utilized.

Individual parenting supportive care interventions

Service provision focused on psycho-socio-emotional based parenting issues commonly reported within research literature (Christ et al., 2015; Zaider et al., 2015). The overarching issue to come to the attention of health care staff was parents' concern for the physical, emotional, social, and psychological well-being of their children. Talking to children about death was least documented, even among patients receiving EOLC. Talking to children about impending parental death is challenging for most families (Hailey et al., 2018) and HPs, however parents often desire HP guidance navigating these difficult discussions but can experience barriers accessing support (Turner, 2007; Turner et al., 2008; Bugge et al., 2009). Research is needed to explore which aspects of parenting patients want guidance with as part of hospital-based supportive care.

The analysis of relationships between clinical, socio-demographic, and psychosocial factors and the type of parenting support provided revealed variances across patient subgroups. Higher child care concerns were noted for parents diagnosed with a poor prognosis within one month of their initial cancer diagnosis. The latter result aligns with descriptive studies stating patients are often focused on adjusting to diagnosis news, medical treatment, and immediate practical issues (Park et al., 2016). Parenting support, however, differed across multiple socio-demographic characteristics. The number (more than two) and age of the children (at least one child under 12 years old) were two characteristics linked with increased support across numerous parenting issues: memory making, quality time, role and responsibilities, talking to children about cancer, child care, and parental sadness, guilt, and worry. Variances by patient age, sex, and religion were few; parents under 50 years old had higher child care interventions, females received increased support for future planning, and parents affiliated with a religion accessed greater assistance with parental role and responsibility concerns.

Psychosocial factors were also indicated; with interventions increased for multiple parenting concerns where patient distress, co-parent, family and EOL issues were reported. Overall these findings pointed to family-based aspects more so than individual patient characteristics being associated with the type of parenting support provided.

Parent subgroups largely underrepresented in advanced parental cancer studies—patients of lower socio-economic status, from CALD backgrounds, males, and single-parents—were evidenced as receiving parenting interventions. Only single-parenting patients were found to have received increased support, this was regarding talking with their children about IESC and future planning; both are recognized as challenging tasks for single parents (Behar & Lewis, 2015). Further studies with larger and diverse patient populations across multiple sites is needed to confirm if such findings are generalizable to a broader parental cancer population. A population-based study assessing the parenting support needs of patients with IESC would also be beneficial in identifying at-risk or vulnerable groups.

Limitations

Numerous limitations to this study. It is a single site study using a nonrepresentative sample. Resourcing, recruitment challenges, and time limitations excluded the possibility of conducting a population-based study. The study sample excluded patients whose parenting status and/or IESC diagnosis was not clearly defined, making it difficult to accurately determine how many patients did not receive parenting-related support. Data extracted from patients' medical records were likely inconsistently documented across HP disciplines; data may also have been missing.

Clinical implications

This research contributes to the parental cancer and palliative care knowledge base as it reflects parenting-focused support practiced as part of routine hospital-based psychosocial supportive care—an area that has received limited attention to date. Our findings validate the emerging evidence that patients with IESC parenting minor

children are not routinely offered parenting-focused services as part of hospital-based palliative treatment however when their needs became visible to a health care team member it appears to trigger an interdisciplinary team response. We offer new evidence that patients of all ages, sex, cultural background, and socio-demographic background access hospital supportive care for their parenting issues. While results are the unique experience of patients attending one tertiary metropolitan hospital, this data together with the documented high burden of parenting and coinciding serious psychosocial issues provides further impetus to the argument that these families need equitable access to parenting-related support during hospital treatment. A first-step clinical response could entail reviewing and strengthening resources prior to introducing systematic screening of patients' parenting status; offering support without an intervention management plan would be unethical. Parenting issues fluctuate during the IESC phase indicating support offers need to be made repeatedly during the course of health care. Comprehensive family-focused psychosocial support that complements in situ supports and strengthens patients' and co-parents' capacity to parent is advocated. Hospitals are fast-paced health care institutions yet they are a common and important intersecting point for parents with IESC and HPs, a space in which parenting concerns potentially impacting on patient's well-being and health care decision-making have the opportunity to be addressed.

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CHAPTER 4

Phase II study: Health professional perspectives

Overview

Chapter 4 explores hospital-based multidisciplinary health professional perspectives on patients' and co-parents' parenting support needs and factors influencing optimal hospital-based parenting supportive care practice.

This chapter comprises the Author's Original Manuscript of an article accepted for publication by NASW Press in *Health & Social Work* (American spelling; references included):

Steiner, V. Shlonsky, A. Joubert, L. & Morris, A. (n.p.). Hospital parenting support for adults with incurable end-stage cancer: Multidisciplinary health professional perspectives.

Author	(%)	Contribution
Vera Steiner	65	Conception and design, analysis and interpretation of data and drafting of manuscript
Aron Shlonsky	15	Conception and design, interpretation of data and critical review of manuscript
Lynette Joubert	15	Conception and design, interpretation of data and critical review of manuscript
Anita Morris	5	Critical review of manuscript

Abstract

Patients with incurable end-stage cancer (IESC) who are parenting minor-aged children often experience parenting-related distress. Parenting concerns are not always addressed as part of routine hospital-based psychosocial care. Currently, we lack multidisciplinary health professional (HP) perspectives in this area. An exploratory study of hospital-based HP perspectives of adult patients' and co-parents' parenting experiences, support needs and parenting supportive care practice was conducted. Twelve multidisciplinary HPs from one Australian tertiary hospital participated in a semi-structured focus group/interviews. Data were audio recorded, transcribed, and finally analyzed using thematic analysis. Results showed HPs were cognizant of patients' and co-parents' diverse parenting support needs and experiences and other aspects which comprise best practice. However, multilevel organization, HP, patient/co-parent barriers impeded optimal practice. Barriers included a non-systemized approach to screening patients' parenting status and parenting support needs, inadequate resourcing, limited professional support, hospital environment, and parent psychosocial factors. Feasible options for addressing practice barriers are provided in this paper. Reviewing what factors influence optimal parenting-focus from interdisciplinary HP perspectives helped identify potential strategies which could influence a shift from medical-focused care to more holistic family-focused patient care.

Keywords: health care, parental cancer, parenting, psychosocial intervention, qualitative

Introduction

Parenthood during the incurable end-stage cancer (IESC) phase is a time of fluctuating distress for patients and their families. Epidemiological data suggest that a significant number of parents face end-stage cancer, with 338,840 adults of child rearing age (20–74 years) dying from cancer in the United States in 2015 (Bray et al., 2018). Parents (patients and co-parents) have been shown to experience higher anxiety and depressive symptoms than their nonparenting counterparts; patient quality of life is worse in the final weeks, and treatment decision-making is affected (Nilsson et al., 2009; Park et al., 2016). Patients commonly face debilitating physical symptoms, taxing treatment regimes, and the ongoing grief and anticipatory loss that inevitably comes with facing a terminal illness (Zaider, Salley, Terry, & Davidovits, 2015). Parents' capacity to protect their children during this period is often put under strain and doubts of parenting competence tend to surface (Semple & McCance, 2010). Supportive care interventions have helped reduce this multidimensional distress by strengthening parents' and children's coping resources (Botti et al., 2006).

Over the past 20 years, international health care developments in cancer and palliative care have resulted in the implementation of psychosocial care guidelines, frameworks, and integration of psychosocial care into routine health care (Holland, Watson, & Dunn, 2011; Palliative Care Australia, 2018; Ristevski, Breen, & Regan, 2011). Some countries, such as Denmark and Norway, have implemented further measures including legislation requiring for all cancer patients to be systematically screened for parenting status and provided child-centered interventions where required (Aamotsmo & Bugge, 2014). Enhanced medical care has led to patients living longer with advanced cancer (National Cancer Institute, 2019), increasing the visibility of parental psychosocial stressors to HPs. Despite the progress, parenting support needs of patients with minor-aged children are still not routinely addressed by HPs (Fearnley & Boland, 2017) and family-focused supportive care is yet to be implemented into routine hospital health care practice in many countries including the US (Muriel et al., 2012), UK (Arber & Odelius, 2018), Germany (Ernst et al., 2013), and Australia.

Few studies have explored multidisciplinary HP perspectives of hospital-based parenting supportive care practice targeting patients' and co-parents' concerns such as, adjusting to changes in their parenting role and responsibilities, talking with their children about the unwell parent's prognosis and dying, and managing parental anticipatory grief. Research has focused on medical and nurse practitioners' perceived barriers in the communication with patients about their children when they are seriously ill (Dencker et al., 2017) and nurses' perceptions of advanced parental cancer supportive care (Turner, et al., 2007b). Two systematic reviews explored HP perspectives of barriers and facilitators of health care psychosocial interventions for families affected by any cancer (Inhestern, Haller, Wlodarczyk, & Begelt, 2016) and interventions for parents experiencing any type of life-threatening illness (Fearnley et al., 2017). Other broader-based studies examined the challenges of incorporating supportive care into routine cancer care (Ristevski et al., 2011) and the barriers to providing psychosocial support to adults with cancer in various settings. However, in these studies, parenting status and children's ages were not documented (Botti et al., 2006; Dilworth, Higgins, Parker, Kelly, & Turner, 2014). Research indicates that parents with IESC or life-threatening illnesses (and their co-parents) desire parenting support from HPs but their needs are not always met for reported reasons such as HPs avoidance of parenting-related discussions, cursory discussions (rather than engaging in more in-depth conversations), and limited knowledge and skills in parenting support and guidance (Turner et al., 2007a). Patient/co-parent, HP, and organization-based factors can all influence HPs' capacity to provide optimal support. These include parents' emotional status (Romer et al., 2007), lack of HP training and education (Turner et al., 2007b), limited resources, and hospital environment including culture (Romer et al., 2007). Multidisciplinary HPs' practice experiences and insights are an important source of information that have the potential to contribute to improving hospital-based parenting supportive care.

Methodological approach

Research question, approach, participants and setting

This study provides an in-depth exploration of the research questions: (a) What are hospital-based multidisciplinary HP perspectives on the parenting experience and support needs of patients (and co-parents) diagnosed with IESC? and (b) What factors influence optimal hospital-based parenting supportive care practice? A descriptive, prospective, qualitative design underpinned by a pragmatic approach (Creswell, 2014) captured multidisciplinary HPs' perspectives. A focus group comprised the primary mode of data collection; individual interviews were conducted with two HPs who were unable to attend due to unforeseen clinical emergencies and personal sensitivities. Purposive sampling was used to recruit 12 multidisciplinary HPs from eight disciplines—medical: oncology, palliative care (n = 2); nursing: oncology, palliative care (n = 3); and allied health disciplines: social work, clinical psychology, occupational therapy, physiotherapy, Aboriginal Health, and pastoral care (n = 7). Ninety-two per cent were female with an average of 19.7 years professional experience. All were employed by one Australian tertiary hospital providing acute and ambulatory oncology and palliative treatment in multicultural western metropolitan Melbourne, Victoria and outlying regions. Participant email invitations were directed to HP managers. Reporting was guided by the consolidated criteria for reporting qualitative research (COREQ) framework (Tong, Craig, & Sainsbury, 2007). The study was conducted as phase II of a three-phased PhD research project—phase I comprised a clinical data mining study on hospital-based parenting supportive care practice and phase III explored patient and co-parent perspectives of parenting support needs and factors impacting on hospital-based parenting support utilization (Steiner, Joubert, Shlonsky, & Hocking, 2020).

Data collection and analysis

A semi-structured interview guide (Table 1) was developed using a three-step process. Topics were first identified from key parental cancer and palliative literature, clinical expertise, and preliminary findings from the phase I study. Open-ended interview

questions were then formulated and themes refined, first through a critical appraisal by two independent expert clinicians (R.L. & M.W.), followed by critical feedback from two of the research supervisors (L.J. & A.S.).

Table 1. Interview guide

Theme	Questions
Parenting status	A. How do you find out if a patient is parenting one or more children aged from birth to 18 years old?
Assessment	B. What do you think are the support needs of patients and co-parents who are parenting these children?
	C. How comfortable are you with talking to patients and co-parents about their support needs as a parent?
	D. What strategies do you use to engage in discussions with patients and co-parents about their parenting support needs?
	E. How important is it to address their parenting concerns?
Intervention	F. What supports have patients and co-parents wanted that is specific to their role as a parent?
	G. What support have you provided to help them in their role as parents?
Other	H. Is there anything else important you would like to tell me that has not been discussed?

Data collection occurred at the hospital in August 2017. Participants signed consent forms detailing study purpose, participant requirements, and its voluntary nature. Human ethics research approval was granted by the hospital's Low Risk Ethics Panel [HREC/17/WH/59]. Interviews comprised one group (n = 10 participants) and two individual sessions, each lasted approximately 60 minutes and were electronically recorded, transcribed, and data managed using QSR NVivo 11 software (QSR International Pty Ltd, Australia).

Data were examined using thematic analysis (Braun & Clarke, 2006); a reflexive, systematic, and transparent method with demonstrated success in health science research (Braun & Clarke, 2006). Using open coding methodology, data reduction was facilitated by dissecting interview transcription textual data into meaningful text segments and codes based on theoretical interests underpinning the research question and related issues raised by the HPs. Basic themes from coded text were clustered, analysed, discussed, and refined by two authors (V.S. & L.J.) and a highly experienced

qualitative researcher (A.H.) to create global themes spanning the dataset using thematic mapping (Braun & Clarke, 2006; 2013).

Results

Qualitative data fell into two main categories: HP perspectives of parents' parenting experiences/needs, and parenting supportive care practice. Each category included thematic clusters organized in descending order of thematic strength and importance that was informed by repetition and expressed significance to participants (Figure 1).

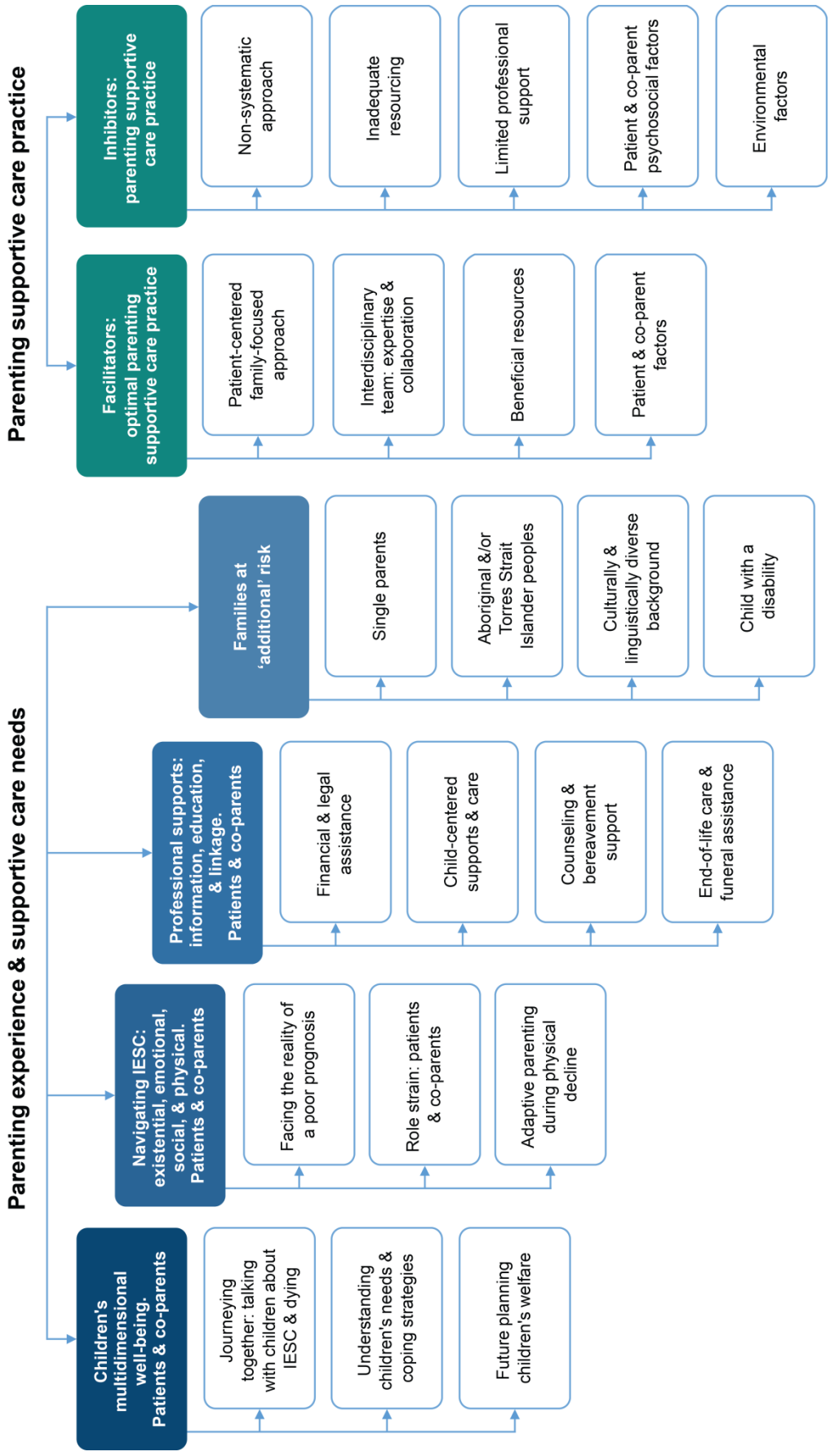

Figure 1. Health professional perspectives: parenting needs and supportive care practice

Patient/co-parent experiences and supportive care needs

Four domains focusing on HPs' perspectives on parents' parenting experience and support needs emerged spanning time from the past, present, and future. HPs' insights indicated a comprehensive recognition of the unique factors of human experience—emotional, physical, social, cultural, and spiritual—that shape each patient's and family's world, and those shared across this patient population.

A. Children's multidimensional well-being: now and the journey ahead

HPs reported that parents expressed significant concerns for their children's current and future multidimensional well-being and worried about how their illness and impending death would affect the children emotionally, socially, and psychologically. Parents wanted HP guidance in communicating with their children about cancer and dying; HPs often initiated parenting-related discussions with parents.

> *We need to open the door and talk about these things… because if you don't start talking then maybe there are some things that they want to tell you, something that they want to discuss, important things.*
>
> (Participant 6)

HPs observed parents' approach to communicating with their children varied, some spoke openly and early post IESC diagnosis while others tended to communicate indirectly when death was imminent. Parents were not always cognizant of their children's support needs or services available. Some sought guidance to understand their children's individual needs and coping strategies. The HPs noted that communication between parents in a family regarding these matters was limited. Requests from parents were often for help with planning their children's future welfare which included financial and legal matters and the organization of quality time. Parents expressed their concerns to HPs about how the children would cope after they died,

what would happen to the children, and what they could do to prepare them for this stage.

B. Navigating the IESC journey: existential, emotional, social and physical challenges

HPs expressed facing a poor prognosis engendered significant grief and loss for patients, both emotionally and existentially. Parents needed support adjusting to disease progression and facing their mortality, which included 'meaning making' and reconciling feelings of guilt and shame. HPs perceived the IESC journey to entail personal existential crises, emotional adjustment, and anticipatory grief conjured by thoughts of leaving their children behind and not seeing them grow up. For co-parents, anticipatory grief and loss centered on the impending loss of their partner and parenting through the period of bereavement. Role strain was commonly witnessed by HPs through observation and discussion with parents; patients faced role changes and co-parents experienced increasingly demanding roles and responsibilities. Single-parent families encountered additional strain and difficulty maintaining self-care. Parenting was challenging for all. When ill parents experienced physical decline and encountered difficulty executing usual physical-based parenting tasks, they asked for quick-to-learn adaptive strategies which would enable them to continue to actively parent before their demise.

C. Engagement with professional supports: information, education and linkage

HPs received regular requests for financial and legal assistance from families primarily due to sudden decreases in income and increased daily living and health care expenses. Parents were in need of community support, service information, and linkage to facilitate service access. Some only sought information to enable self-sourcing. HPs stated parents typically desired practical tools, strategies, and resources to enable them to talk with their children about IESC cancer and dying. Sometimes they expressed the need for direct HP support to talk with their children.

Sometimes it's actually about me sitting with them [parents] and supporting them through that [talking with children].

(Participant 2)

Other needs entailed creating and/or strengthening linkage with general, cancer-based, and mental health child-centered community services (including schools and program: CanTeen, Camp Quality, and Head Space), and addressing present and future childcare needs. Family-focused counseling and bereavement support was required, including funeral assistance and end-of-life care advocacy. HPs indicated that parenting support needed to be responsive, family-focused, culturally sensitive, delivered across the hospital and transitioned into the community.

D. Families at 'additional' risk

Four family clusters were identified by HPs as being at 'additional' risk of distress. They were: a) single-parents; b) Aboriginal and/or Torres Strait Islander origin; c) culturally and linguistically diverse (CALD) backgrounds; and, d) child/ren with a disability. HPs stated single parents required support navigating intense emotional and practical stressors. These included concerns and anxieties about their children's future welfare; financial concerns; uncertain future child care arrangements; and, placement of children in out-of-home care if the parent was assessed as too ill to manage core parenting tasks. HPs expressed their own concern for the well-being of children responsible for the primary care of their parent. HPs recognized that parents of Aboriginal and/or Torres Strait Islander origin perceived hospitals as unsafe spaces. They feared child removal based on historical trauma due to colonisation in Australia. Parents feared being judged incapable of continuing parenting due to their deteriorating physical function, particularly if they were single-parenting.

> *One of the perhaps greatest fears, is that if you've got end of stage [cancer]... there is that real fear that child protection will come in and take your kids.*
>
> (Participant 11)

HPs perceived CALD families as facing numerous risks: use of family interpreters meant ill parents may be shielded from receiving important medical information during family meetings, and HPs reported that young children were often primary carers and used as health care interpreters for their parent. They were often exposed to stressful situations with minimal support. Families raising a child with a disability were observed by HPs to have limited support networks, substantial caring responsibilities that affected parent capacity to attend their own health care appointments, and these parents were less likely to seek professional supportive care assistance.

Optimal parenting supportive care practice

HPs universally reported having high motivation to provide optimal parenting-related support. Nurses and medical practitioners mentioned that they were the earliest contact with parents and because of this were best positioned to initiate parenting status identification including seeking children's ages.

A. Facilitators: factors that support optimal practice

Four basic themes emerged as factors HPs perceived to facilitate optimal parenting supportive practice. They were: a) patient-centered family-focused approach; b) interdisciplinary team with expertise and high levels of collaboration; c) beneficial resources; and, d) parent and co-parent factors. Optimal practice was considered to entail a patient-centered family-focused approach that was integrated into routine care and offered in a holistic, flexible, and tailored way to respond to individual parents' and families' specific needs across the IESC and bereavement phases.

> *It's about opening the door and letting them identify what's important to them and most of the [time] there's been a variety of things… it can just be so varied that there's no, I suppose, set script for it… so you've just got to be flexible.*
>
> (Participant 12)

All HPs conceded the importance of supporting parents' control over their IESC health care journey and for the care to be family-focused and patient-led. Rapport and trust were paramount and best developed over time if possible, with due consideration of a family's cultural background. Once established, HPs felt more comfortable initiating sensitive discussions. Various elements facilitated rapport building and parenting-based discussions. These included formal assessment processes, less formal bedside conversations, and a conducive hospital environment. Aspects considered to be advantageous included an ethos of cultural and spiritual sensitivity, safe and private therapeutic spaces for families as well as, a child-friendly atmosphere. Appropriate environments enabled HPs to successfully advocate for parents' preferred place of death and assistance with convening child-friendly funeral ceremonies within the hospital campus.

Participants described their interdisciplinary approach as largely collaborative and supportive; working towards a shared goal of providing quality care to the family unit with each discipline's input being uniquely valued as an integral part of the team. HPs considered that implementation of successful parenting practice in this area entailed being cognizant of their own and other HPs' skillsets, knowledge, resources, and having confidence and comfort discussing parenting topics. These recommendations from HPs included making early referrals to colleagues with specialist skillsets and utilizing evidence-based parenting intervention information. Effective communication was key across all the clinical processes (including parenting status identification, screening, referrals, needs assessments, interventions, case discussions, discharge planning, and community integration) and practice forums (including interdisciplinary meetings, informal collegial case discussions, and patient medical note documentation). HPs indicated that discussing disease progression and prognosis with patients and families

required a team approach. The approach entailed first assessing parents' and co-parents' prognosis understandings, and deciding on the most optimal strategies for delivering news and engaging families (including children) in an open discussion. Family meetings featured as a common forum for discussions regarding inpatient and outpatient settings and were convened with patient consent. An interdisciplinary approach to care within and across the hospital and community settings was considered as being fundamental to the parents' health care journeys which tended to oscillate between settings. Proactive team responses to addressing identified parenting-focused service gaps led to improved care outcomes for parents and their families.

> *We have a clinical checklist. We had to approach the Cancer Council Victoria [for it]... we have a list of all the psychosocial supports they offer and I find that handy to give to patients and also they can be quite specific then.*
>
> (Participant 9)

The fourth subtheme 'beneficial resources' details four main aspects HPs considered to promote quality care that was absent from current practice. They included: a) adequate clinical time (e.g., to develop a therapeutic relationship, unpack parenting concerns, and provide guidance, resources and referrals at the parent's pace); b) allocation of dedicated outpatient psychosocial supportive care staff (i.e. allied health professionals and nurse coordinators); c) range of accessible hospital and community-based parenting resources (e.g., child- parent- and family-focused psychoeducational information, counseling, support groups, family meetings, and practical assistance—child care, finances, legal); and, d) utilization of culturally-specific resources (e.g., "Aboriginal-specific" [Participant 11]).

The final subtheme—patient and co-parent factors— revealed that HPs found parents were open to discussing parenting issues, volunteering their parenting status and concerns when comfortable and given sufficient time, and agreeable to receiving guidance when feeling uncertain about how best to support their children. Parents were seen as exhibiting significant strength and resilience, demonstrating their strong desire

to protect their children, and resolving issues pragmatically. HPs emphasized the importance of building on co-parents' strengths and resiliency in parallel, by providing them with sensitive therapeutic supports which were complementary to their existing coping strategies thereby, giving them the ability to continue on with good parenting after the death of the parent.

B. Inhibitors: factors that impede practice

Thematic analysis revealed five basic themes detailing features that HPs perceived hindered parenting supportive practice (Figure 1). A description of the subthemes underlying the basic themes are presented in Table 2. Varied multisystem factors—organization level, HP, and patient/co-parent—were perceived by HPs as influencing parenting supportive care practice across the inpatient and outpatient hospital settings.

Table 2. Health professional perspectives: factors hindering parenting supportive care practice

Basic themes	Subthemes
Non-systematic approach	• Ad hoc processes: from initial screening to bereavement support • Parenting support needs are not equally viewed as a clinical priority across HP disciplines & hospital system • Screening and assessments influenced by: reason for referral, clinical setting, & factors (such as, incidental disclosure during treatment or review of carer arrangements) • Parenting status identification & age of children: not routinely asked on hospital presentation; varying ways used to ask, record, & communicate among team members; data not always accurately recorded or easy to locate in patient medical records • Bereavement-related support was not part of routine practice

Basic themes	Subthemes
Inadequate resourcing	• Human resource shortfalls & clinical time pressures across inpatient & outpatient hospital services (medical, nursing & allied health disciplines) • Gaps in family-based & child-centered supportive care: hospital & community • Working beyond scope of practice & skills training, & HP funding (e.g., medical HPs) • Cultural workers not routinely used to engage with vulnerable patient populations (e.g., Aboriginal &/or Torres Strait Islander peoples) • Inequitable access to allied health/supportive care staff across various hospital treatment areas (e.g., outpatient services) & different cancer streams (e.g., nursing cancer coordinator not funded for all) • Ethical practice concerns: offering parenting support in the absence of available resources • Limited parenting supportive care training (e.g., experienced HPs felt confident discussing with patients & co-parents but less experienced were not) • Professional interpreters are not always readily available; children/family members used instead
Limited professional support	• Formal supervision deemed essential but access variable across HP disciplines: some frontline staff reliant on informal collegiate support & self-sourcing • Self-care practice & debriefing was crucial given nature of work was emotionally & psychologically taxing; confidence & knowledge did not alleviate being affected • Vicarious trauma: danger of 'giving of yourself' to enhance the patient-HP relationship without recognition of the effect on self • Ethical practice dilemmas often experienced that contravened professional and personal views (e.g., social justice issues: witnessing dying parents' inequitable access to needed parenting resources; children not being told the parent is dying)
Patient & co-parent psychosocial aspects	• High levels of parental emotional & behavioral distress, avoidant style coping, protectiveness of children, & gatekeeping behaviors by family make engagement in parenting support difficult • Talking about death & dying was difficult for many families. HPs concerned of detrimental effect that concealment can have on family members, particularly the children • Parents equating support as giving up hope (e.g., telling children prognosis news, future planning) • Historical trauma & cultural backgrounds of parents/families affected their feelings of safety regarding open discussions, particularly if rapport & trust had not yet been built (e.g. Aboriginal people felt judged or culturally unsafe, needed HPs to spend time to listen to their story first before discussing sensitive parenting matters) • Late initial engagement with HPs during active palliation phase resulting in expedited intensive support interventions of limited scope (e.g., children informed the parent is dying at short notice—limited time for HP to prepare children & engage supports)

Basic themes	Subthemes
Environment	• Inpatient setting: chaotic, noisy, & lack of privacy (e.g., in shared-bed wards) affected ability to discuss sensitive parenting issues • Limited indoor child-friendly spaces • Hospital setting can be unsettling for adolescent children with mental health issues

Interpretation

Unlike previous research this study delivers a uniquely interdisciplinary HP perspective on parenting-focused practice. HPs were cognizant of the inherent complexities faced by patients and co-parents (Aamotsmo et al., 2014) juggling parenting tasks while concurrently addressing past-, current-, and future-based psychosocial issues and navigating existential, emotional, social, and physical changes (Zaider et al., 2015) throughout the disease trajectory. Parents' concerns for their children's multidimensional well-being was prominent (Park et al., 2016). Patient, co-parent, and families' need for—and general receptiveness to—receiving HP guidance and support was observed (Bugge, Helseth, & Darbyshire, 2009; Fearnley et al., 2017; Turner et al., 2007a). In this study, identification of families at 'additional risk' shed light on how social inequities and cumulative adversity can compound health and well-being vulnerabilities (Public Health England, 2017) and the importance of reducing such influences by routinely providing hospital-based psychosocial parenting support. HP-parent conversations involving prognosis, death, and parenting were confronting and challenging for HPs and parents (Hailey et al., 2016; Turner et al., 2007b). The findings highlighted influential cultural and spiritual aspects which are seldom reported in parental cancer intervention research and the relevance for culturally safe and trauma-informed practice.

HPs' perspectives presented both a best practice wish-list as well as full comprehension of the realities of daily practice in this area. Interventions oscillated between being proactive and reactive. Optimal practice was accomplished sometimes but was unsustainable due to various multilevel system factors—patient/family, HP, and organization. This echoed many social features presented within adult cancer and

palliative care literature (Dencker, et al., 2017; Dilworth et al., 2014; Inhestern et al., 2016; Ristevski et al., 2011). HPs' experiences were not only challenging due to the emotional nature of parenting supportive practice but with how services are provided. Parenting status and support needs screening was often not systemized across and within HP disciplines and health care teams. Two qualitative studies interviewing medical and nursing HPs (Arber et al., 2018; Dencker et al., 2017) indicated such barriers are amendable with changes to screening procedures and staff training. Parenting-related interventions tended to be influenced by HP preferences and perceived abilities (Dencker et al., 2017; Fearnley et al., 2017), interdisciplinary communication, treatment settings, situational factors, and availability of culturally appropriate resources. The latter included culturally safe therapeutic spaces, cultural workers, and professional interpreters. Ethical concerns regarding routinely screening patients without being able to equitably offer parenting-related support services were emphasized by HPs; however, issues regarding patient privacy did not surface concerning the disclosure of family details. Keeping disclosure optional could be any easy option to mitigate such concerns. HPs expressed how parents' decisions regarding whether and/or when to disclose prognosis news to the children sometimes contrasted their personal views and their knowledge of parent-child communication research evidence (Inhestern et al., 2016). Such patient-HP value conflicts reveal the complexities of working in an emotionally laden environment and the importance of ongoing skills training and supervision.

Strengthening HP practice

Defining a clinical pathway and developing procedures to routinely identify patients' parenting status and parenting supportive needs, alongside the delivery of HP training and education could assist with addressing various barriers experienced. Structural changes can help transform emotional and organization culture factors hindering practice (Dencker et al., 2017). Leadership from a HP discipline with psychosocial expertise (e.g. social work) could help drive change via a multi-staged interdisciplinary quality improvement (QI) project. Likewise, securing better acceptance of a dynamic collaboration within the hierarchy of the hospital (Romer et al., 2007) would be a priority. Project objectives could potentially target referral pathways and screening,

assessment and intervention procedure development, HP education and skills training, parenting guidance resources for HPs and parents, and clinical supervision review. Strategies could include systemizing screening processes (Dencker et al., 2017) whereby patients' recorded parenting status is flagged each time their e-medical record is opened, as well as the development of a parenting support practice guideline as an adjunct to existing psychosocial practice guidelines (NBCCCI, 2003). Existing and accessible evidence-informed resources—HP education and training programs, parenting resources, and interventions (Turner et al., 2008; Massachusetts General Hospital, 2019)—could potentially be adapted (Romer et al., 2007; Inhestern et al., 2016). Establishing or utilizing existing collaborative partnerships with universities and community agencies to support the QI process and address service gaps could be other beneficial options.

For social work practitioners interested in adopting a parenting-focused practice approach, changes could be readily implemented in several areas. Parenting-related questions could be incorporated into patient referral and assessment forms and processes (for example, Parenting status? Age and number of children? Any patient/co-parent parenting concerns? What [formal/informal] parenting supports do you/they have? Are they helpful? What other parenting support do you/they need?). A Parenting Resource Kit for Parents could be developed featuring a fact sheet describing hospital- and community-based parenting supports available for families facing advanced cancer and how to access them, as well as educational information focusing on parenting during advanced cancer. Further, the development of a one-page Social Work Guide to Parenting Support with tips for sensitively engaging with patients and their families about parenting matters, and engagement in targeted parenting supportive care training could enhance parenting-focused practice competencies.

This study has several limitations. It was a single-site exploratory study with a single focus group and two interviews and therefore the views of HPs presented may not be widely generalizable. In this regard it would be helpful to know how these results might vary across metropolitan and rural hospital settings. Thus, wider scale studies are warranted. There was no observation of HPs' behavior in practice—all findings are

based on self-reporting. The focus group captured shared viewpoints but may not have captured individual perceptions or discussion of sensitive themes (e.g., poor practices; insecurities about competence). Sex differences among HPs may also be present, not captured in this study as our sample only included one male HP. The broad analysis of multisystem factors impeding and facilitating optimal parenting practice is likely to have omitted other important aspects within each level. A comparative analysis of HP perspectives on how parenting supportive care practices differed across inpatient and outpatient settings may have provided a richer examination of factors influencing practice, potentially useful for identifying areas requiring service improvement.

Future research is needed to undertake surveys with larger HP populations across different sites and geographical locations. These would include an observational exploration of interdisciplinary processes underpinning optimal parenting supportive care in the inpatient and outpatient hospital settings, an exploration regarding how HPs' personal and professional values and beliefs of death and dying influence their supportive care decision-making, and finally the development of models for brief trauma-informed parenting interventions.

Practice implications

This study builds on existing research evidence, highlighting significant multifaceted and complex challenges faced by multidisciplinary HPs endeavouring in delivering often complex parenting supportive care as part of routine hospital-based psychosocial care. Strategies which encompass an interdisciplinary HP team approach and leadership by the social work profession in targeting screening and referral pathways could assist in formally systematizing the identification of patients with IESC and offering of parenting support. The enhancement of HP efficacy through conducting family-focused assessments and interventions, staff education and skills training as well as, the establishment of evidence-informed resource development could prove beneficial as steps for driving practice change and enhancing the well-being of patients and their families. The findings of such work may also be applicable to a wider range of health professions.

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CHAPTER 5

Phase III study: Patient and co-parent perspectives

Overview

Chapter 5 explores patient and co-parent perspectives on parenting support needs and experiences and factors influencing optimal hospital-based parenting supportive care practice.

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Lynette Joubert	15	Conception and design, interpretation of data and critical review of manuscript
Aron Shlonsky	15	Conception and design, interpretation of data and critical review of manuscript
Alison Hocking	5	Interpretation of data and critical review of manuscript

Abstract

Parenting support needs of patients diagnosed with incurable end-stage cancer (IESC) with young families are not addressed as part of routine hospital health care. Their support needs and experiences of hospital-based parenting support are largely unknown. The study aims to explore hospital-based parenting support delivery from patient and co-parent perspectives in context to their parenting experience and support needs. Exploratory, prospective, cross-sectional qualitative design. Semi-structured in-depth interviews with eight adult patients with IESC and four co-parents purposively recruited from a tertiary hospital in Melbourne, Australia. Findings were thematically analysed. Parents desire support with challenging multidimensional parenting issues. Organization, health professionals (HP), and parental-based factors hinder and facilitate optimal service provision. Responsibility rests with HP to initiate parenting support. Interdisciplinary family-focused support offered throughout IESC health care journey is key. Patient-centered family-focused support is warranted. Surmountable challenges lie with management and HPs to address barriers affecting optimal service delivery.

Keywords: health care; hospital; palliative care; parental cancer; parenting; psychosocial intervention; qualitative

Introduction

Cancer remains one of the leading causes of death worldwide (World Health Organization, 2015). With increasing survival rates due to advancements in cancer treatment (National Cancer Institute, 2019) and postponement of parenthood in many developed countries (Gotze et al., 2017; Inoue et al., 2015), the likelihood of parents raising children while facing incurable end-stage cancer (IESC) is anticipated to increase. In 2019 it is estimated 49,896 people would die from cancer in Australia, 14% of whom will be aged under 60 years old (Australian Institute of Health & Welfare, 2019) and within parenting age. In the United States, 338,840 adults of child rearing age (20-74 years) died from cancer in 2015 (Bray et al., 2018), with around 55,000 children experiencing the loss of a parent (Phillips & Lewis, 2015).

Many adult cancer patients with incurable end-stage cancer—defined as stage 4 cancer stage where curative treatment is no longer the goal of care—raising minor children experience distress related to their premature death, and the impact their illness and death will have on their families (Bell & Ristovski-Slijepcevic, 2011; Park et al., 2016). Parenting concerns of palliative cancer patients are well established (Park, Stephenson, Moore, Deal, & Muriel, 2019) and supported by growing research revealing the negative psychosocial impact advanced parental cancer can have on the family unit and members within it. The health and psychosocial complexities of living with IESC can cause parenthood to become challenging (Park et al., 2016) and family functioning significantly disrupted (Zaider, Salley, Terry, & Davidovits, 2015). Ill parents are at increased risk of psychological distress (Park et al., 2019), poorer quality of life, and health care treatment decision-making can be influenced (Check et al., 2017; Nilsson et al., 2009). Co-parents face psychological distress (Aamotsmo & Bugge, 2014) and children are exposed to increased risk of serious psychological and emotional distress (Morris, Martini, & Preen, 2016; Rainville, Dumont, Simard, & Savard, 2012).

The unique parenting concerns encountered during IESC can temper parenting confidence and competence (Bugge, Helseth, & Darbyshire, 2009; Semple & McCance, 2010). Of the few evaluated psychosocial supportive care interventions involving

parents with IESC (Steiner, Shlonsky, & Joubert, 2017) targeted support delivered by health professionals (HP) was indicated to contribute to parent psychosocial well-being and parenting confidence, with beneficial psychosocial outcomes for children (Bugge, Helseth, & Darbyshire, 2008). A recent systematic review confirmed parents want guidance and support with parenting when facing a life-limiting illness but it is not routinely offered in health care settings (Fearnley & Boland, 2017). A second study investigated HP and researchers' perspectives of barriers and facilitators influencing utilization of psychosocial interventions for families with parental cancer (Inhestern, Haller, Wlodarczyk & Begelt, 2016). Parenting supportive care can be offered within hospital-based care by the interdisciplinary team but there is little research either clarifying or describing effectiveness from the team or consumer perspective.

Understanding patient and families' experiences are an important resource for improving quality improvement (Institute of Medicine, 2001) of multidisciplinary cancer and palliative parenting supportive care. Existing studies illustrate the complexity of psychosocial issues impacting on parenthood during the IESC phase (Zaider et al., 2015) and provide some insight into what patients and co-parents want HP assistance with (Bugge, Helseth, & Darbyshire, 2009; Turner, et al., 2007), unmet supportive care needs (Ernst et al., 2013). However, they lack deeper perspective of patient and co-parent experiences and viewpoints of hospital-based parenting-focused support and the inconsistencies between patient expectations and services offered, and factors influencing optimal parenting supportive care. This study aims to explore in-depth the research question: What are the perspectives of patients diagnosed with IESC and their families of hospital-based parenting-related supportive care, their experiences and supportive care needs, and what factors facilitate and hinder optimal parenting supportive care? It is an attempt to elicit useful data that can inform clinical practice and guideline development to better address well founded parenting concerns of this vulnerable patient population.

Method

Design

This study utilized a prospective, cross-sectional, descriptive qualitative design using semi-structured interviews, underpinned by a pragmatic approach (Creswell, 2014). Reporting is guided by the consolidated criteria for reporting qualitative research (COREQ) framework (Tong, Craig, & Sainsbury, 2007). Themes reported in this study form part of a larger dataset exploring topics related to parenting-focused support for hospital patients with incurable end-stage cancer and their co-parents who are raising one or more children aged up to 18 years old.

Ethical considerations

Human ethics research approval was granted by Western Health (WH), Melbourne, Australia [HREC/17/WH/59] and all 12 participants signed consent forms detailing the study purpose, participant requirements, and its voluntary nature. Significant attention was given to ethical considerations during all stages of the research process. Recruitment was sensitively conducted by the primary participants' medical team and interviews conducted by a trained HP researcher external to the organization. Participants selected interview times and location, all were advised they could terminate their involvement at any stage. Using a semi-structured interview guide enabled the interviewer flexible navigation around delicate topics. All participants were provided additional support service information and offered a referral to a health professional as needed.

Participants

A purposive sample of eight patients and four co-parents were recruited at a large, government funded, tertiary metropolitan hospital in Melbourne, Victoria, Australia. Participants comprised adult patients with incurable end-stage cancer (any type) who were accessing noncurative hospital treatment and parenting one or more children aged up to 18 years old; adult co-parents were nominated by the patient. Diverse clinical and

socio-demographic patient characteristics were sought with sampling including cancer type and staging, sex, age of children, country of birth, English and non-English speaking. Patients too unwell or unable to give informed consent were ineligible.

Data collection

Oncology and palliative care medical teams screened patients attending inpatient and outpatient hospital services for potential eligibility to participate in the study. Eligible participants meeting inclusion criteria were invited to participate by their medical team and those interested were referred to the researcher (V.S.) and a full explanation provided and written consent obtained; all participants were offered reimbursement for parking fees. Consenting patients and co-parents were interviewed individually, except for one patient/co-parent dyad who preferred a joint interview; all participant preferences were actioned.

Eleven in-depth, one-off interviews, ranging from 13 to 57 minutes duration (M = 30 minutes) were completed and conducted by the interviewer (V.S.) from October 2017 to December 2017 (setting: inpatient n = 1; outpatient n = 10). The interviewer was an external researcher with no prior or existing relationship with the hospital; the study was conducted as partial completion of a PhD research project funded through an Australian Government Research Training Program Scholarship. A semi-structured interview guide (Table 1) was developed using a three-step process. Open-ended interview questions were informed by key themes derived from parental cancer and palliative literature and preliminary findings from a clinical data mining study focusing on parenting-related support received by adult hospital patients with IESC conducted by one author (V.S.) and critically appraised by two authors (L.J. & A.S.) and two independent expert allied health professionals (R.L. & M.W.) with hospital-based practice experience and no relationship to Western Health. Interviews were completed using a flexible and sensitive approach, drawing on techniques from narrative interviewing (Gunaratnam & Oliviere, 2009) to gently encourage and elicit discussion. Initial immersion in the raw data were completed by one author (V.S.) during data collection to enable familiarization with the overall key themes emerging. Interviews

were digitally recorded, transcribed, and imported into QSR NVivo 11 software for management (QSR International Pty Ltd, Melbourne, Australia).

Table 1. Interview guide

Theme		Questions
Parenting status identification	A.	Did you tell the health care team that you are a parent with children aged under 19 years old?
Assessment	B.	As a parent what supports have you needed during this palliative phase?
	C.	Are you comfortable talking to a health professional about what you need help with as a parent?
Intervention	D.	As a parent, what support have you received from health professionals to help you, your partner/co-parent and/or children?
	E.	What support has been most helpful to you and your family?
	F.	What support would have been helpful, that you and your family did not receive?
Other	G.	Is there anything else important you would like to tell me that has not been discussed?

Data analysis and theoretical framework

Thematic analysis (Braun & Clarke, 2013) was selected due to its pragmatic, reflexive, systematic and transparent method of revealing the salient patterns of meaning from the data being studied and proven successful application in health science exploratory research (Herzog, Handke, & Hitters, 2019). Using open coding methodology, data reduction was facilitated by dissecting interview transcription textual data into meaningful text segments and initial codes assigned. Coding was based on the issues raised by participants and the theoretical interests underpinning the research question (i.e., parents' experiences and views of hospital-based parenting support) and influenced by the primary researcher's lens: Australian middle-class, middle-aged female parent who is a social work practitioner-researcher. Similar codes were distilled into one group. Basic themes were developed from clustered coded text and theme weighting was informed by repetition and emotional significance to participants. Themes from individual interviews were consolidated, analysed, discussed, and refined by three authors (V.S., L.J. & A.H.) to create global themes spanning the dataset (Braun

& Clarke, 2013) using thematic mapping (Braun & Clarke, 2006). Privacy and confidentiality were protected by the removal of identifying names.

Results

Participants and setting

Nineteen eligible participants were invited to participate in the study (Figure 1) and 12 consented and were interviewed, representing a response rate of 63%. The eight patients were diagnosed with seven different types of cancer and were living with an IESC diagnosis for an average of 10 months (range: 0.25–34 months). The average age of parents was 43 years and co-parents was 55 (overall range: 28–65 years). Participants were parenting a total of 19 children aged (0–18) years old (M = 10.3 years); average 2.4 children per family unit. Five (42%) participants were born overseas; English was the primary language for 11 (92%). No interpreters were required.

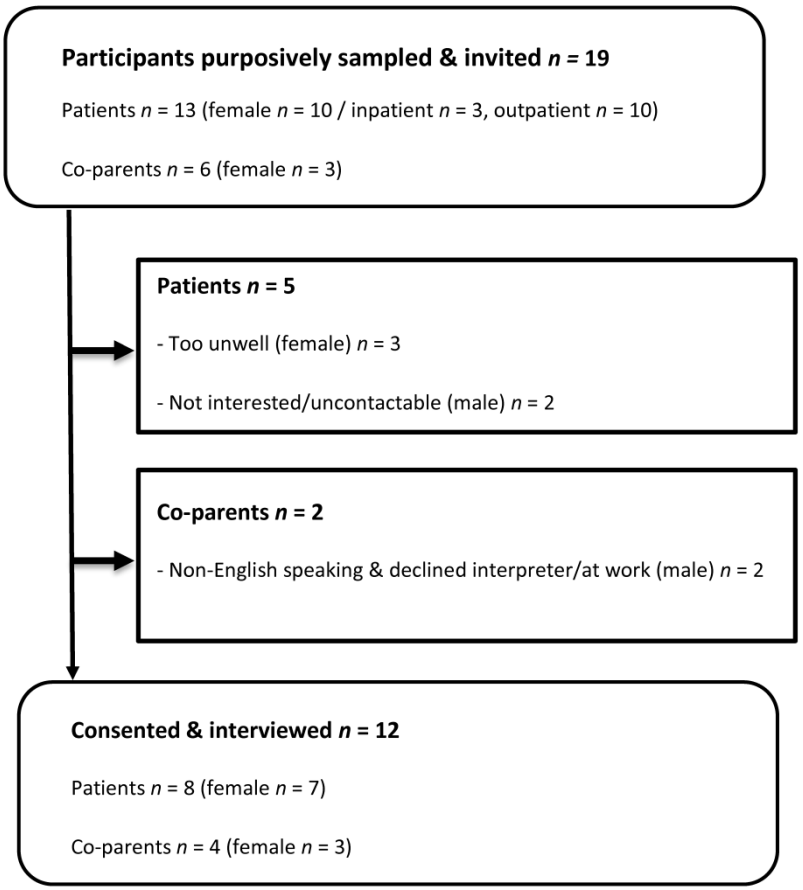

Figure 1. Recruitment flowchart

Key findings

The qualitative data fell into two main categories: (a) parenthood during IESC phase: the lived experience and supportive care needs and (b) parenting-focused supportive care utilization. Figures 2 and 3 show the global themes and basic themes within each category, arranged in descending order of thematic strength based on the frequency of topic discussion and emotional significance to the participants determined by the length of time discussing the topic and level of emotional expressed.

Parenthood during IESC phase: lived experiences and parenting support needs

Five global themes highlight patient and co-parent parenthood experiences during the IESC phase and their past, present, and future parenting supportive care needs that evolved from the analysis of data.

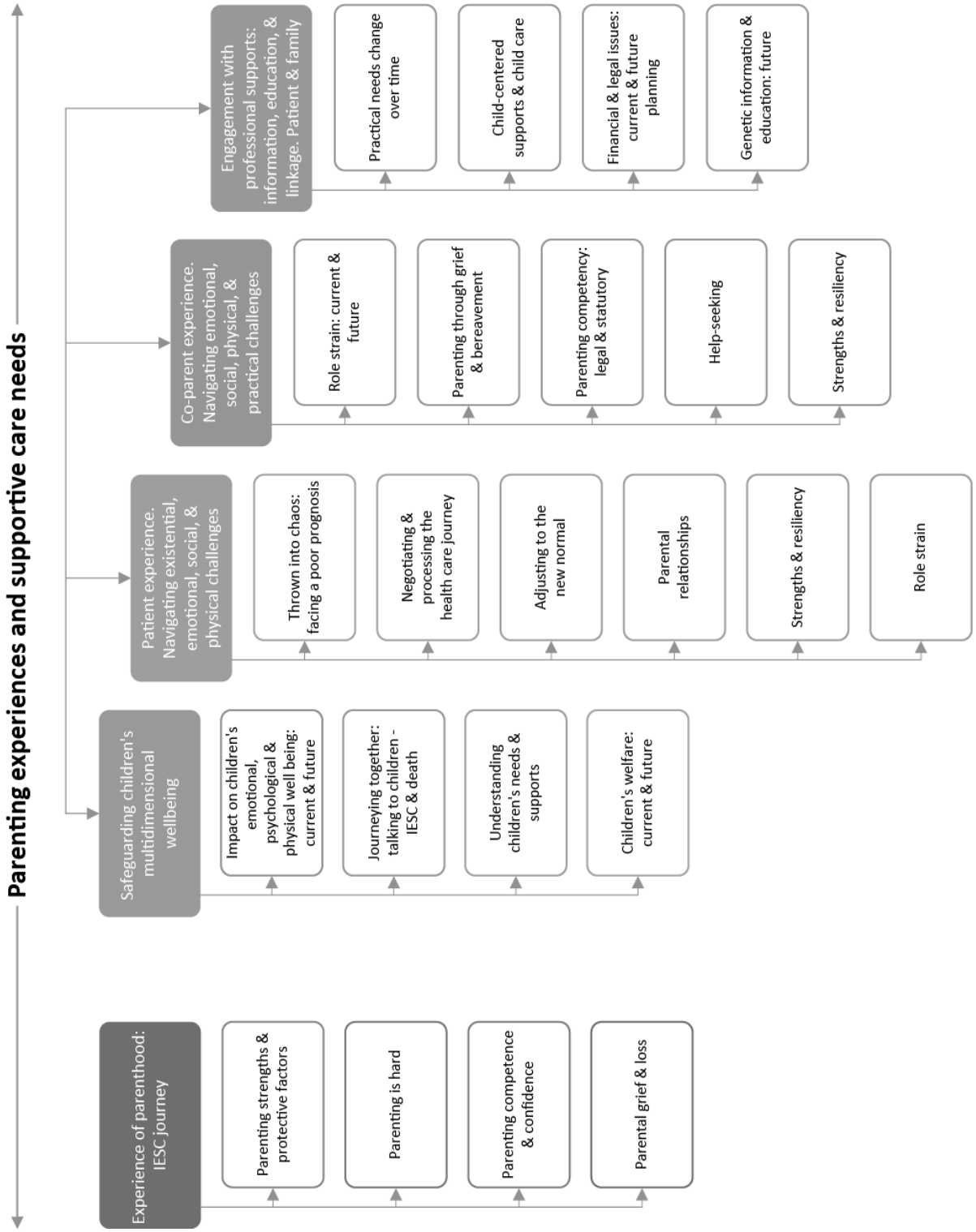

Figure 2. Parenting experiences and supportive care issues

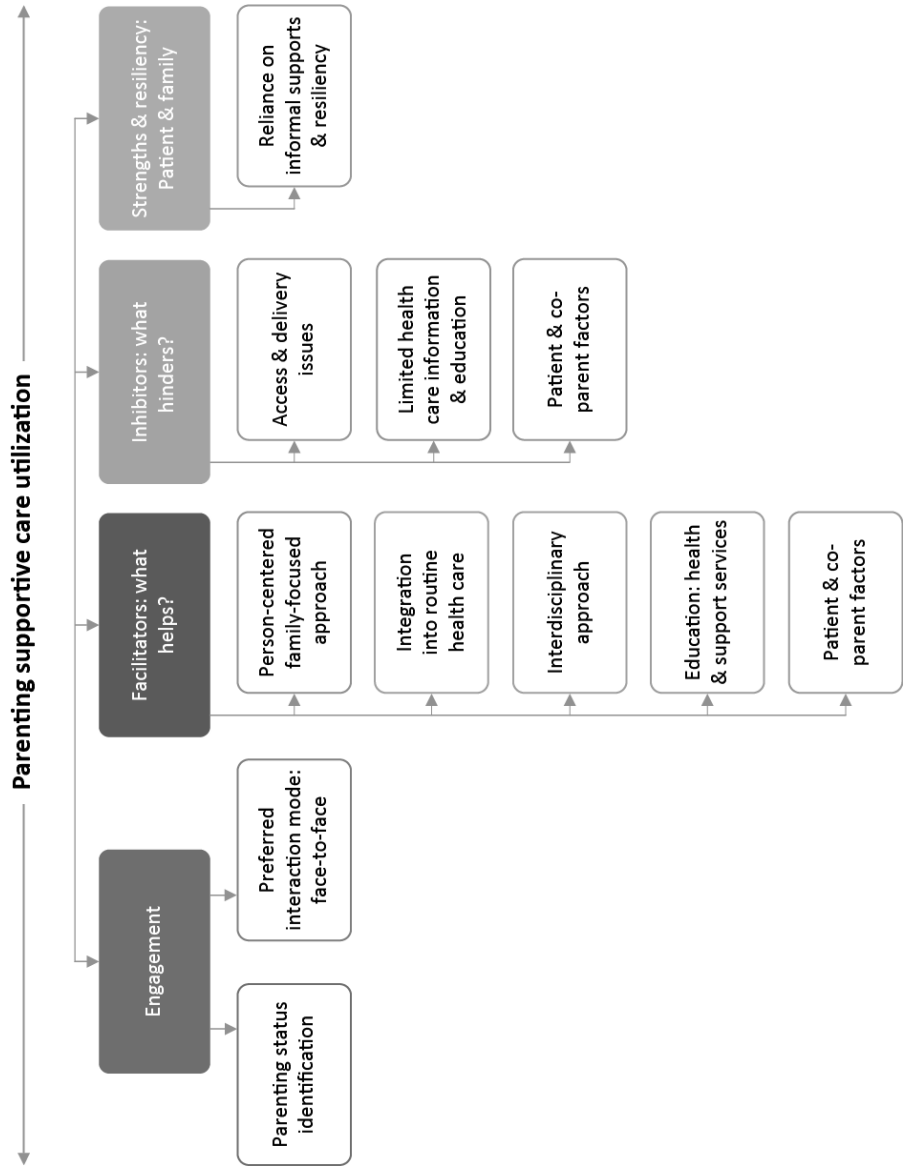

Figure 3. Parenting-focused supportive care utilization

A. Experience of parenthood: IESC journey

Parenting strengths and protective factors: Overall parents voiced their strong drive to protect their children's multidimensional well-being despite encountering situations when parenting was not prioritized over self-care and survival during periods of initial IESC diagnosis, deteriorating health, and debilitating treatment side-effects. Narratives of strength and insight were revealed through positive accounts of their spiritual and religious faith, their own and co-parents' parenting capacity, and self-awareness of their limitations. Parents generally recognized and accepted their children could benefit from supplementary care and support beyond what they could provide and utilized

temporary assistance via informal and formal community-based resources (e.g., family, friends, school, and child-focused cancer services), finding informal support most helpful. Parents were both weighed down by parental responsibilities but indicated their children were a protective factor, giving them a reason to hold onto hope and engage in opportunities that could enhance their length of life, their mood, and quality time together. Parents detailed their pragmatic approaches to dealing with various parenting adversities encountered.

Parenting is hard: Descriptions revealed parenting was challenging throughout the IESC journey, every day bringing a different set of challenges. The period of IESC diagnosis was particularly difficult with parents adjusting to the news and endeavouring to shield their children from their shock, sadness, and worry; distressed how their illness and death would impact on their children. Aside from navigating direct parent—child matters, disparities regarding parenting approaches and communication were present between parents, particularly with openly disclosing the terminal nature of the cancer, adding further tensions. Parenting roles continually morphed; co-parents anticipated changes would extend through the palliative period into bereavement and beyond. Responsibilities entailed being cognisant of, and responding carefully to, each child's individual support needs (e.g., including based on personality, developmental phase, and emotional adjustment) while normalising life to enable children to continue to "live life". Witnessing separation anxiety in younger children made hospital-based treatment a stressful experience. All parents conceded that single-parenting compounded parenting hardships emotionally and practically.

Parenting competence and confidence: Parents conferred concerns of being a 'good enough' parent; this was more apparent for patients than co-parents. Parents provided detailed successful accounts of educating and supporting their children since the IESC diagnosis yet felt they were underperforming at times. Parenting during the IESC was experienced as an expedited and steep learning curve, parents reporting being unsure at various points how best to support their children's emotional, social, behavioral, psychological, spiritual, and practical needs. The initial period post IESC diagnosis was highlighted as a time when parents were often too distressed or undergoing health care

treatment to initiate support for their children; patients effectively single-parenting (with physically and/or emotionally absent co-parents) advised that HP initiated child-centered support helped facilitate parenting competency. Self-doubt regarding parenting efficacy was more apparent in this parent subgroup.

Parental grief and loss: Narratives described the anticipatory grief experienced by parents contemplating leaving their children behind when they died; fear of losing parenting independence, control, and rights (patients and co-parents); own feelings of separation anxiety from their children when receiving hospital care; being too biomedically toxic to physically connect with and nurture their children; coping with resurfacing parental loss and traumas (e.g., child loss through death and estrangement); and, parental relationship breakdown.

B. Safeguarding children's multidimensional well-being

Impact on children's well-being—current and future: Parents reported their children were exposed to innumerable stressors and experienced significant emotional turmoil and disrupted developmental milestones throughout the IESC phase. Stressors included witnessing their parent's health deteriorate, receiving overwhelming psychosocial support, having multiple and revolving carers, and separation from their parent during treatment and hospitalisations. Parents wanted to understand the genetic and toxic impact of cancer and treatment side effects would have on their child's current and future well-being, and worried how parental death would affect their children:

> *It's just… mortality, the gap that I'm going to leave and the damage it's going to cause [the children].*
>
> (Male patient, co-parenting)

Journeying together—talking with children about IESC and dying: Parents experienced emotional and practical difficulties explaining disease progression and dying to their children, viewpoints regarding the optimal timing and openness of disclosure varied across and within families; some parents censuring their language to distance

themselves from death while others talked directly about their impending death. Journeying together was an active process negotiating child—parent, parent—parent, and intra-familial communication dynamics. Disparities existed between parents regarding their understandings of their children's awareness that one parent was dying. One set of parents from the same family stated:

> *The older ones know. The other ones are too young to understand... It's just she doesn't understand the concept of it. And I, look, when I feel it's time I'm going be going, I'll explain it to them then.*
>
> (Male patient, co-parenting)

> *There's also the two little ones, they understand. We explained that [their father] has cancer and probably won't be here long. So, they're just trying to, like, live day-by-day with [him].*
>
> (Female co-parent)

Parents in acceptance of their poor prognosis utilized it as an opportunity to impart preventative health education to their children.

Understanding children's needs and available supports: Parents reported their children's support needs differed across their individual developmental phases and IESC phase. Challenges included being unsure what support their children wanted and needed, understanding what child-centered supports were available, managing children's behavioral changes and adolescents' refusal to engage with accessible community-based child-centered cancer support services.

Children's welfare—current and future: Subthemes spanned from planning and securing their children's financial future through accelerated 'nest building', with sole family providers planning to work until they are physically unable while other parents focused on creating quality time with children and preserving positive memories. Some adolescents helped shoulder their welfare needs and family financial stressors by

working. Legal matters pertaining to the creation or updating of Wills, enduring powers of attorney, and guardianship were common.

C. Patient experience. Navigating the IESC journey: existential, emotional, psychological, social, and physical challenges

Thrown into chaos—facing a poor prognosis: Receiving the news that treatment had transitioned from active to noncurative threw many families into chaos, conjuring feelings of fear and uncertainty. Patients expressed being concerned of parenting alone irrespective of whether they were partnered or not; none were ready to die. Emotional overload and focus on medical treatment was a typical response immediately following IESC diagnosis. For some, having an uncertain future and experiencing depression affected their ability to plan. Managing projected fear from HPs, family, and others providing support was heightened distress:

> *I could feel their horror. And it's almost like they were very tentative about explaining the extent of my disease. But at the same time, you know, I kind of often felt I wanted to say to people, 'Look, this is... You know, this is my body. This is mine. I'm not scared of it right now'. And I don't need to feel as though everybody has to speak in hushed tones and, you know, even referring it to like 'end-of-stage cancer'... there was always a sense that—yeah, of other people's fears being projected onto you... it was just like a feeling of, 'Hang on, I own this and it's all right'.*
>
> (Female patient, single-parenting)

Negotiating and processing the health care journey: Managing pain and treatment side effects was likened to a roller coaster ride. Energies were spent maintaining control of the health care journey; health literacy and timely information was needed.

Adjusting to the new normal: Emotional and psychological adjustment to fluctuating health status was a continuous process for patients and family. Adjustment entailed

coping with changing physical appearance and deteriorating function, life review, settling unresolved prior grief, and meaning making. For some, stress-induced cognitive impairment influenced the process.

Parental relationships: Narrative subthemes featured patient's concerns for the co-parent's well-being; experiences of enhanced emotional bonding through shared grief; parental relationship breakdown—extra emotional and practical support was needed; and avoidance of death-focused conversations among parents:

> *[Co-parent] knows I'm dying, we don't-we don't talk about it. We try to kind of, I don't want think about it... there's nowhere we won't go, we just don't talk about it.*
>
> (Female patient, co-parenting)

> *I don't even know what [patient] knows [poor prognosis]. You know, I mean my understanding is, it's probably two years at best.*
>
> (Male co-parent)

Strengths and resiliency: Patient and co-parent strength and resiliency was underpinned by their focus on hope; strengthening of familial relationships; reliable supportive informal care (family and friends) for patients, co-parents, and children; and, religious and spiritual faith. Patients expressed confidence in their children's future welfare when they perceived the co-parent as having parenting competency.

Role strain: Patients faced considerable challenges constantly balancing self-care with parenting roles, prioritizing children's health care needs over their own. Multigenerational caring responsibilities compounded role strain.

D. Co-parent experience. Navigating the IESC journey: emotional, social, physical, and practical challenges

Role strain—current and future: Co-parents experienced multifaceted pressures, juggling increased responsibilities in their concurrent roles such: a co-parent, partner/significant other, carer, health care advocate, multi-generational carer, resource researcher, and attending to the broader psychosocial needs of the family. Most co-parents reported how co-parenting and caring impacted on their own health. Older co-parents (patient's parents) envisaged role strain would continue into the future when they transitioned into a more primary parenting role when the parent died. Related strain included sensitively managing guardianship issues, negotiating child care options, and holding the responsibility of supporting the children while the parent is dying, the bereavement period, and beyond:

> *You don't know what to plan for it and think about [death]. You know it's probably inevitable. Yeah, it's going to happen sooner or later… it will be bad enough, but not being able to get the children through it appropriately too…*
>
> (Male co-parent)

Parenting through anticipatory grief and bereavement: Challenges entailed parenting with their own anticipatory grief while parenting by putting on a brave face for the patient and children. Factors affecting parenting comprised supporting the children during the illness, death, and bereavement; normalising life for the children and creating opportunities for them to have fun prior to the parent dying; memory making in the face of hope; and the lack of information from health professionals (HP) and family communication regarding prognosis:

> *It's tough stuff. So, yeah, that's a hard thing of not knowing what the prognosis is… we have asked [medical team] several times but no one will really commit and say anything.*
>
> (Male patient, co-parenting)

Parenting competency—legal and statutory: Several co-parents with existing mental health disorders, prior involvement with child protection services, and/or ongoing guardianship applications faced numerous legal and statutory issues wherein they feared their parenting efficacy would be judged by authorities and ultimately determine if the children would remain in their care when the parent died.

Help-seeking: Co-parents viewed family as their core emotional and practical support. Formal emotional support from the hospital or community agencies were experienced with varying views of helpfulness. Unmet parenting-related support needs remained an issue for co-parents whether English and non-English speaking.

Strengths and resiliency: Countering the dynamic and ongoing co-parenting stressors required constant adjustment; co-parents focused on consciously making every day count and drew strength from the resiliency and courage exhibited by the ill parent.

E. Engagement with professional supports: information, education, and linkage.

Patient and family

Practical needs change over time: Supports needed to be responsive to patients' fluctuating physical status over the course of the IESC phase and family members' changing psychosocial needs; practical supports needs were described as primarily domestic and transport-related. Crises were viewed as avoidable through proactive practical support. Having practical assistance—formal and/or informal—enabled parents to spend quality time with their children and conserve energy:

> *It's hard when you've got kids, to try and research stuff yourself… someone else can help me do it… People have got limited time with the kids. You don't want to be research something if you can spend the time with your kids.*
>
> (Female patient, co-parenting)

Child-centered supports and child care: HP guidance, information, and education about talking with children about IESC and dying was a top support request by parents; they sought detailed advice and direct guidance. They wanted HPs to offer information and education about available hospital and community-based parenting supports including child-inclusive counseling, and how to negotiate formal community-based child-centered support systems (e.g., schools) and services. Child care assistance for families with young children was often needed when parents attended medical appointments, were hospitalized, and experienced impaired functioning; all participants used friends and family to meet their child care needs but cited concern for parents less fortunate, querying what overnight child care is available. HP assistance with internet and social media education for children was also requested—children had viewed web-based cancer information unsupervised whilst the parent was hospitalized during the IESC diagnosis period which served to amplify their fear.

Financial and legal planning—current and future: Co-parents wanted HPs to provide information and linkage to community-based financial and legal services; primary legal issues related to Guardianship, Wills, and Enduing Power of Attorney. Advocacy and support with negotiating community agency bureaucratic processes was another area of support required for which HPs had been helpful.

Genetic information and education—future: Parents wanted to be provided genetic education regarding the potential impact on their child's future health and well-being; no HP support had been offered. It would assist with future planning, enabling parents themselves to know how to talk with their children about these genetic issues.

Parenting-focused supportive care utilization

This section discusses emergent themes from participants' experience and perspectives of what parenting support would likely be of benefit to their own family and others. Prior to study participation all parents had received at least one hospital-based parenting support intervention since their IESC diagnosis, interventions were supplementary to the support provided by family and friends, and community-based services. At the time of interview most parents reported past and present unmet parenting support needs.

A. Engagement

Parenting status identification: Participants reported HPs had initiated all discussions about parenting status. All except one parent confirmed being asked within three weeks of IESC diagnosis; following this most parents were asked multiple times over the course of their illness. Different methods were used by medical, nursing and, allied HP to determine parenting status—medical/allied health assessments including informal bedside discussions, observation of family visiting the hospital, and pre-existing health care notes. All parents felt comfortable disclosing their parenting status to any HP however one patient felt embarrassed initially due to her family situation but this quickly changed due to sensitive inquiry by the HP:

> *I felt very supported and so there was no reason from their end for me to be uncomfortable about it but I just, I suppose I felt like embarrassed, myself, about my circumstances [poor parental relationship]... so if there was any awkwardness, it was coming from me, actually revealing all these issues because it's never really been something I've revealed.*
>
> (Female patient, single-parenting)

All welcomed future screening and appreciated early offers of parenting assistance post IESC diagnosis regardless of their decision to engage with support.

Preferred interaction mode: All patients and co-parents found it most helpful and comfortable engaging with HPs face-to-face regarding parenting matters. One patient described it as enabling a therapeutic connection between parent and HP, also providing an opportunity to screen the clinician prior to the children accessing their support. However, having time available to participate was an influencing factor for HPs and families. Parents indicated phone-based interventions were comfortable and usually helpful but interactions lacked depth. There was a mixed response from parents regarding whether they would access web-based parenting supports despite acknowledging such resources could be helpful and offered flexibility for time-poor patients and co-parents.

B. Facilitators

Patient-centered family-focused approach: All participants perceived patient-centered family-focused parenting support offered as part of their hospital health care throughout the IESC phase as beneficial to their well-being and their children. High importance was placed on building rapport, respect, and trust with HPs to facilitate this and having autonomy and control over parenting supportive care utilization—particularly intervention type and timing—and the power to accept or decline without jeopardizing access to future health care services. This was particularly important for participants with trauma, mental health, and child protection histories; rationale for a trauma-informed (Lawson & Lawson, 2018) interventions. Parents perceived optimal support to be comprehensive, tailored, flexible, and responsive to patients', co-parents', and their children's emotional and practical needs during the IESC journey and not delivered in a "too textbook" way. While direct support for children was infrequently offered, it was viewed as a safety net for when children were uncomfortable engaging with school-based or child-centered cancer services, or where appropriate child-inclusive services are unavailable. A family-friendly hospital environment was strongly desired, one parent attested to how a hospital tour had helped reduce their child's fear of hospitals and demystified the treatment regime. Ideas for enhancement included parents being given treatment scheduling preference if parenting children with their own high level health care needs.

Integration of parenting support into routine health care: Parenting support offered as part of routine health care treatment was desired as hospital HPs were perceived as having a better understanding of the parenting issues within the disease context than general community-based HPs. Although not always provided, parents wanted to be offered a range of parenting-focused information (hospital and community), education, and services along the disease trajectory irrespective of whether HPs thought they may be well supported.

Interdisciplinary team approach: Interdisciplinary parenting support was described by parents as helpful as different disciplines imparted different knowledge, skills, and practical parenting tools. Having diverse support from a range of HPs helped open up hard to talk about topics and things parents had not yet considered themselves. Parents believed that when HPs worked as a team it aided in the delivery of quality and sensitive supportive care—specific needs of parents can be targeted and delicately addressed with consideration of their situational context. Utilization of professional interpreters for non-English speaking parents was crucial with assisting them to engage in a meaning way with HPs that could help ease feelings of isolation.

Education—health and support services: Parents wanted to be offered parenting service information from HPs rather than relying on self-sourcing, indicating it could waste precious time otherwise spent with their children. Preferences were for HPs to offer educative information with the option to discuss the material together:

> *When you're in the hospital, go to a different room and have a sit down and start to take a look [parenting information]. It could be anything from brochures... but tailor it too. Don't just give [parent] everything that you've got... tailor it to them. If they've got older kids, 'well this is the better one to go to'... A conversation. I think that would be the best way to go.*
>
> (Female patient, co-parenting)

Prognosis information was interlinked with parenting information provision. Experiences of, and responses to receiving prognosis information were varied. Some patients reported the prognosis news delivery was executed tentatively, unclearly, without empathy, or not at all, causing additional distress. Underlying all accounts was the narrative that prognosis discussions helped facilitate a review of parenting support needs, and resources, and setting of priorities.

Patient and co-parent factors: Participants' attitudes indicated an openness to receiving HP parenting guidance and support, including family interventions delivered by suitably trained hospital staff. Facilitating factors were participants' drive to protect their children, insight into their situational parenting capacity, and trust in HPs skills and knowledge. Most participants were accepting of support from any HP discipline capable of providing them with information, education, practical tools, and strategies that could maintain and/or strengthen their parenting efficacy. Accessibility was an essential factor that helped facilitate service utilization.

C. Inhibitors

Access and support delivery issues: Most participants were unclear of what hospital-based parenting support was available to their family, how to initiate support, and navigate 'the system'; irrespective of how long they had received hospital health care and their perceived friendliness and approachability of hospital staff:

> *You don't know where to go to for the help... How I'd get in contact with them... I wouldn't have a clue where to go...I wouldn't know where to start... I wouldn't know who to ask for help or where to go.... I don't know if, what, help could they provide... I didn't know anything was available.*
>
> (Female patient, co-parenting)

Parents expressed feeling distressed when parenting support did not match their needs—type, timing, level, speed, and quantity. Inequitable access to support resources

emerged as a barrier: parents observed some cancer care streams had more supportive care staff employed such as nurse cancer coordinators; co-parents were often excluded and required to find their own community-based support with limited success; and, direct child support was offered haphazardly. Inadequate delivery of services proved distressing on occasion and included—not receiving parenting support offers soon after IESC diagnosis, dealing with HPs projected fear and discomfort expressed through verbal and body language, being given an information package including talking to children about death without being offered HP support. Being identified as a parent by hospital HPs did not guarantee timely access to needed parenting support:

> *A social worker came around for the first time about three weeks ago.... First time in two and a half years.*
>
> (Female patient, co-parenting)

Limited health care information and education: Parents identified multiple gaps specific to the parenting-related supportive information and education they received. Outstanding topics included how to keep children safe from the toxic exposure while parenting following health care treatment; preparation for engaging in age-appropriate discussions with children about genetic issues; and, strategies for supporting and supervising children's internet access of cancer-based information.

Patient and co-parent factors: Fluctuating physical, mental, psychological, and emotional well-being, multigenerational carer responsibilities and time, work commitments, language, historical health service experiences, professional background, gender, personality, trust, and time availability were factors that emerged as influencing patients' and co-parents' engagement with parenting support services. Gatekeeping was evident across all families and influenced help-seeking behavior; it was based on fear—wishing to maintain privacy, control, and protectiveness. Parents' readiness to discuss parenting-related concerns and needs specific to end-of-life varied; within families, parents had divergent views on open communication about death and dying; accessing external supportive care proved difficult, as did poor parental communication regarding what parenting supportive services were already being utilized:

Look my wife may have come across a few. Probably hasn't accessed them too much, but, yeah. No, I don't [know].

(Male co-parent)

D. Strengths and resiliency

Patient and family. Reliance on informal supports and resiliency: Patients and their families heavily relied on the compassion, practical, and reliable assistance from their family and friends to support them to protectively care for their children; informal supportive care was deemed very helpful. Parents expressed deep gratitude for not being reliant on the health care system for primary parenting support.

Study limitations

This study is limited by its cross-sectional design and the corresponding representativeness of the sample, which was fairly small. Participants were recruited from one tertiary hospital primarily servicing one metropolitan geographical location, making generalisation to other hospital settings limited. All participants were English speaking, few were male, and all had existing support networks external to the hospital. Although all patients were identified through the hospital, few inpatients were interviewed due to the fact that hospital admissions are related to acute incidents or for procedures that would make it difficult to interview at that time. Comparative data analysis between inpatients and outpatients was not possible. That said, lack of research on hospital-based parenting supportive care practice with the IESC patient population raising minor children necessitated an exploratory study. Larger scale studies with patients from diverse socio-demographic backgrounds particularly those underrepresented and inpatients/outpatients would likely be helpful for guiding future practice.

Discussion and conclusion

This investigation is among the first to specifically explore interdisciplinary parenting support provided as part of routine hospital-based healthcare to this particular patient population from the experiences and perspectives of patients and co-parents. Results indicate that parenthood following an IESC diagnosis is a challenging and distressing experience for patients and co-parents in shared and diverse ways, similarly reported by Aamotsmo and Bugge (2014) and Park, Deal, et al. (2017) in their studies focused on co-parents and qualitative studies exploring parenthood during metastatic cancer (Bell & Ristovski-Slijepcevic, 2011; Park, Check, et al., 2017). Parenting stressors are multidimensional and dynamic throughout the IESC journey, changing with disease progression and symptoms, treatment side effects, emotional and psychological adjustment, familial, and environmental factors. Parents draw on their knowledge, skills, strengths, and existing resources to manage parenting tasks but can find that additional specialized HP support and guidance was helpful throughout the IESC trajectory; support needs and service utilization varying within and across families, hence necessitating a tailored responsive approach.

While HPs may anticipate elements of parenting concerns and support needs (Arber & Odelius, 2018), understanding what parenting assistance patients and co-parents want from their hospital interdisciplinary health care team is unknown. Parents indicated their comfort with and interest in having their parenting needs assessed repeatedly during the palliative stage; and valued early offers of parenting support following their terminal diagnosis irrespective of HPs' viewpoints. In this study, parenting interventions were not always experienced as optimal. Organization and HP factors such as access difficulties, services not matching their support needs, and HPs' behaviour made the experience challenging. Findings indicated that parents' gatekeeping and help-seeking behaviour influenced parents' utilization of parenting supports as well as their perceptions of service delivery inadequacies. Poor inter-parental communication regarding children's support needs and support service information presented as another factor.

Ideally, parents wanted sensitively delivered family-focused support that complemented their existing informal and formal supports, strengthened parenting efficacy and family functioning, and upheld their locus of control. The overarching narrative confirmed improvements at the organization and HP levels could potentially reduce discrepancies between wanted and received supports, facilitate a positive health care experience, strengthen parenting efficacy, and promote family well-being through the palliative journey. Satisfaction was reported when interventions were comprehensive, tailored, and responsive to parenting-related psychosocial needs of the families throughout the course of the IESC journey and delivered respectfully and compassionately utilizing a patient-centered approach; viewing the experience of disease and symptoms as a component of patients' primary concerns. A qualitative study investigating evidence informed family-focused interventions for parents with IESC (Bugge, Helseth, & Darbyshire, 2009) report similar findings. Participants valued receiving timely parenting support from different HP disciplines, recognizing their different perspectives and expertise regarding therapeutic interventions, information, education, practical strategies, and linkage with additional resources. Pivotal to successful engagement however was having a safe therapeutic environment, free from HP projections of fear and insecurity.

Parents perceived various health care system factors as barriers to optimal parenting supportive care. The primary inhibitors comprise hospital procedures, resource availability, and HP education and training—similarly reported by HPs in studies conducted by Dencker et al. (2017) and Fearnley (2010); all that requiring investment from policy and funding bodies, hospital management, and HPs to address. Despite these challenges of routinizing psychosocial care as part of hospital health care and the appeal of parenting consultancy services offered as an adjunct to routine psychosocial supportive care within hospital settings such as the US-based *Parenting At a Challenging Time (PACT) program* (Massachusetts General Hospital, 2019) and Australian-based *Parent Matters* (Peter MacCallum Cancer Centre & CanTeen, 2019), our data highlights that an integrated, patient-centered, tailored, and responsive interdisciplinary parenting supportive care model is a practice approach welcomed and required by

parents and their families to assist them to address vital concerns affecting their well-being during the challenging and momentous palliative phase.

This exploratory study offers the position that parenting-focused supportive care offered as part of routine hospital-based health care is highly warranted and beneficial to the well-being of parents with IESC and their families. A patient-centered approach is pivotal to ensuring each families' unique needs are respected and guide decision-making regarding all aspects of parenting supportive care. Parents valued the expert health-related parenting support offered by the interdisciplinary health care team as it addressed support gaps not met through formal and informal community-based resources; however, many preferences and support needs remained unmet. The social work profession, underpinned by values and principles espousing compassionate, holistic, patient- and family-centred care practice and expertise in psychosocial interventions is uniquely positioned to take a leadership role in the support of these families during the palliative stage (Loscalzo, Clark, & Bultz, 2015). Strategies could include driving change so patients' parenting status is systematically screened, documented and communicated, and multidimensional parenting support is offered routinely based on a comprehensive parenting needs assessment. Ensuring multidisciplinary practitioners have access to a range of parenting support resources and ongoing tiered education and skills training in screening, assessment and interventions are among several ways to better meet these families' needs and preference. Future research using a mixed-methods design to explore HPs' fears and death anxiety with respect to delaying prognosis discussions with parents of young families facing advanced cancer could also help inform the development of training and education programs.

This study demonstrates the incongruence between patient-centered and evidence-informed IESC phase parenting supportive care and provides directions from parents on what is meaningful and useful, and how practice could be enhanced. The challenge facing hospital management and HPs is how to bridge this gap and optimally engage with palliative patients to help reduce their distress and promote family functioning and well-being into the future.

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CHAPTER 6

Discussion and conclusion

> *You don't know what to plan… and think about that [death]. You know, it's probably inevitable. Yeah, it's going to happen sooner or later, and I think we'll need – yeah, you know, it will be bad enough, but not being able to get the children through it.*
>
> (Phase III study: parent)

Introduction

The parenting context of adult patients is not always visible to hospital-based health professionals and therefore optimal supportive care responses to patients and their families may not meet some of the primary parenting support needs of these families. Death is a part of life, however it is not usually expected to occur during parents' child-raising years. When you have dependent children, a poor cancer prognosis can raise unique issues that are different from those experienced by patients without parenting responsibilities. It is most parents' greatest fear—to die before their children reach adulthood. The evidence aligns with clinical wisdom that patients facing IESC experience increased psychosocial distress (Park et al., 2019), as do their co-parents (Nilsson et al., 2009; Yopp et al., 2015) and children (Huizinga et al., 2011; Krattenmacher et al., 2014); essentially when a parent faces terminal cancer it is a family experience.

This mixed method sequential design research project sought to explore: What parenting supportive care services are offered as part of routine interdisciplinary hospital-based palliative cancer care to adult patients raising minor-aged children? This final chapter summarises the research project comprising the three interconnected study phases. First, an overview of the individual study phases addressing the three sub-questions is presented. Following, the synthesised project findings are discussed in relation to previous research and original findings. Implications for practice and future research are then outlined. Finally, key strengths and limitations of the thesis are described providing further contextualisation of the contributions of this study and potential directions for future research.

The first study phase (Chapter 3) explored the documented parenting and psychosocial support needs of these families made visible to the multidisciplinary health professional team, the parenting supportive care service response delivered as part of routine hospital-based palliative care treatment and identified service trends. Earlier studies have explored parenthood experiences and parenting concerns during IESC (Bell et al., 2011; Hailey et al., 2018; Park, Check et al., 2017; Park et al., 2016; Park et al., 2019; Turner et al., 2007a; Zaider et al., 2015), including the influence of parenting status on treatment decision-making and quality of life (Nilsson et al., 2009) however there are no known published studies that have examined hospital-based parenting supportive care practice delivered as part of routine hospital-based palliative care treatment.

The second study phase (Chapter 4) investigated hospital-based multidisciplinary health professional perspectives on parenting supportive care provided to adult patients diagnosed with IESC and their co-parents using semi-structured interviews:

- What are multidisciplinary health professional perspectives on parents' parenting experiences and supportive care needs?
- What factors influence optimal parenting supportive care?

The few contemporary studies examining health professional perspectives have primarily focused on specific parenting issues and hospital-based interventions (Arber

et al., 2018; Dencker et al., 2017), such as parent's communication with their children from medical and nursing viewpoints (Turner et al., 2007b). This study examines the viewpoints of the interdisciplinary healthcare team on a broader scope of parenting supportive practice offered as part of routine hospital-based healthcare, capturing what influences professional responses and how services could potentially be enhanced.

The third study phase (Chapter 5) comprised semi-structured interviews with patients and co-parents that explored their lived experiences of parenting during IESC and perspectives of hospital-based parenting supportive care:

- What are parents' and co-parents' parenting experiences and supportive care needs?

- What factors facilitate and hinder optimal parenting supportive care?

In contrast to previous parenting intervention studies, such as those examining structured and time-limited parenting programs specifically for parents with terminal cancer and young families (Bugge et al., 2009), this study explores patient and co-parent parenting supportive care needs and their experiences of parenting supportive care delivered as part of routine ongoing hospital-based healthcare. It includes an exploration of their parenting needs—met and unmet—within this context, and considers consumer viewpoints on what factors hinder and facilitate optimal parenting supportive care practice, including suggestions for service improvement. It posits parenting support as an integral element of psychosocial supportive care.

Summary of key findings: Individual study phases

The project features three sequential connected studies that were designed to capture different perspectives of the research issue—a quantitative study followed by two consecutive qualitative studies. Each study phase was conducted individually, with data collection and analysis completed independently. The results of the first study phase were used to assist with formulating the research questions posed in the succeeding phase and so forth. The summarised key findings of each quantitative and qualitative

phase are individually reported here and a synthesised summary of the project findings is then discussed.

Phase I study: Hospital-based interdisciplinary parenting practice

Findings from this initial study uncovered that patients diagnosed with IESC whose parenting issues were documented were of varied clinical and sociodemographic backgrounds (including cancer type, parent age, sex, country of birth, parenting status and income/occupation), with the majority linked to informal supports. On average patients were 47 years old and were raising two children aged up to 18 years old. Results revealed the significant presence and multidimensional scope of parenting concerns similar to reports by patients and co-parents in qualitative studies (Bugge et al., 2009; Park, Check et al., 2017). Insights from the longitudinal data revealed that parenting issues arose over the course of the IESC treatment phase alongside other pressing and often complex psychosocial stressors. Trends identified suggested that no particular clinical and sociodemographic factors tested were related to whether parents received parenting support; however, they together with psychosocial factors were associated with type of parenting support provided (categorised by parenting issue). While 23% of patients in the clinical data mining study had no reported hospital-based parenting supportive care, for the remaining participants (77%) where parenting issues came to the attention of the treating team an interdisciplinary response appeared to be triggered. Potential areas identified for improving hospital-based parenting supportive care practice included reviewing and strengthening resources prior to introducing a systemised approach to screening patients' parenting status and offering patients comprehensive family-focused supportive care throughout the IESC treatment journey.

Phase II study: Multidisciplinary health professional perspectives

This second study revealed that the multidisciplinary health professional team were largely cognisant of parents' diverse and challenging parenting and psychosocial support needs, including family-based issues. Overall, they viewed that raising parenting concerns was a dual responsibility of patients/co-parents and health professionals. Several patient subgroups were identified as at 'additional risk' of

distress—single-parenting, Aboriginal and/or Torres Strait islander origin, parenting a child with a disability and those from culturally and linguistically diverse (CALD) backgrounds. Practitioners voiced their viewpoints on what comprised evidence-informed parenting supportive care practice however conceded it was not always achievable in practice. Multiple organisation, health professional and patient/co-parent factors emerged as barriers including—nonsystematic approach to screening patients' parenting status and parenting support needs, inadequate resourcing, limited professional support, hospital environmental factors and various patient and co-parent factors. Appraising these factors along with the perceived facilitators of optimal parenting support—patient-centred family-focused approach, interdisciplinary team with high levels of collaboration, beneficial resources and patient/co-parent aspects—pointed to potential areas for enhancing hospital-based parenting supportive care practice.

Phase III study: Parent perspectives

Parenting was described as uniquely stressful and challenging at times. End-of-life stage parenting concerns and psychosocial stressors were explicit and fluctuated throughout the IESC journey. Patients and co-parents desired to be good parents, acting to protect their children's current and future wellbeing. Despite their strengths and resiliency parenting confidence and competence waivered at times. Collectively parents welcomed emotional and practical parenting support and guidance, favouring tailored patient-centred family-focused delivered by an interdisciplinary team offered as part of their IESC healthcare journey. Retaining autonomy to accept or decline parenting intervention offers was essential to parents. All parents had unmet parenting supportive care needs despite having accessed supportive care; co-parents' needs were often overlooked. Multiple organisation, health professional and patient/co-parent factors were perceived to hinder and facilitate optimal parenting supportive care provision. Proposed changes included systematic screening of patients' parenting status and health professionals assuming a proactive role in sensitively instigating parenting support discussions.

Summary and discussion: Parenting experience findings

Examination of the data across the three studies revealed broad similarities and differences on key aspects of the parenthood experience during IESC, parenting concerns and the psychosocial context within which parenting occurred. The results are discussed in this section.

Experience of parenthood during the IESC phase

The parenthood experience was indicated as largely challenging for both patient and co-parents throughout the IESC phase for similar and different reasons. Both patients and co-parents raising dependent children up to 18 years old have been shown to have higher incidences of anxiety when one partner is diagnosed with cancer (Götze et al., 2017). These results revealed that both shared a deep concern for their children's' wellbeing however patients experienced existential and also anticipatory grief and loss associated with their declining physical capacity to fulfil parenting tasks and contemplating leaving their children. Co-parents, too, encountered feelings of grief and loss, however themes of significant role strain, bereavement and work-related issues were prominent. These differing challenges reflect findings from contemporary research studies focused on the impact of IESC on well co-parents (Aamotsmo et al., 2014; Park, Check et al., 2017). The mutual protectiveness of parents, together with their divergent supportive care needs and different understandings of their children's support requirements highlighted the relevance of hospital-based parenting supportive care being co-parent inclusive and pointed to the possible benefits of individual and joint parenting supportive care interventions. Co-parents in other studies have expressed wanting advice and guidance from health professionals, such as when and how to tell the children their parent was going to die (Aamotsmo et al., 2014). Further investigations are clearly required to fully explore co-parents' supportive care needs—their parenting issues, communication within families about parenting concerns during advanced cancer (Park, Deal, Yopp, Edwards, Stephenson et al., 2017; Park, Deal, Yopp, Edwards, Wilson et al., 2017) and what factors influence their utilisation of hospital-based parenting supportive care services. With a deeper understanding of such core

issues together with existing knowledge, supportive care services can be developed to be more responsive to the breadth of parenting complexities faced by these families.

Overall, parenthood during the IESC stage was experienced as a time of non-normal transitioning rather than one of pathology as often described in the parental cancer research literature (Lewis, 2007). Parents drew on strength, resiliency, protective factors, informal resources and support services to assist them to navigate the personal, parental, and familial-based challenges that spanned from physical to psycho-socio-emotional-existential domains during the IESC treatment and bereavement phase. Common challenges centred on coping with disease and treatment symptoms, impaired physical function, adjustment to the terminal diagnosis and prognosis (Park, Check et al., 2017); balancing self-care with parenting responsibilities (Bell et al., 2011), role strain (Aamotsmo et al., 2014; Bell et al., 2011) and parental loss and grief (including anticipatory grief) (Semple et al., 2010). Studies exploring family functioning in families where parents are living with terminal illness have shown that family adaptation and resilience is common (Möller et al., 2014; Schuler et al., 2014); despite the known disruptions that may occur to the family life cycle and delayed developmental stages of individual family members (Rolland, 1994; Carter & McGoldrick, 1998). This study found that utilisation of hospital-based parenting supportive care was viewed as a means of guiding and strengthening patients' and co-parents' parenting capacity and also directly supporting children when parents' own resources were exhausted for example, due to illness, demanding treatment regimes, or know-how. For parents who are palliating, psychosocial stabilisation of the family unit needs to be an essential goal of healthcare (Kühne et al., 2013).

Characteristics and diversity of parenting concerns

This study demonstrated that parenting issues that came to the attention of health professionals were dynamic across the IESC phase for individual families. This was made evident through examination of longitudinal data documented in 30 patients' hospital medical records from the point of IESC diagnosis to their death; health professionals' and parents' retrospective accounts also confirmed that issues waivered along the

palliative treatment stage. These project results build on the combined evidence from prior research and clinical expertise that has described how parenting concerns may arise at different junctures along the disease trajectory—at IESC diagnosis (Turner et al., 2007a; Russell et al., 2012b), as physical function deteriorates (Zaider et al., 2015), when children's' support needs change due to developmental phases and coping (Russell et al., 2012a), the differing times when parents feel uncertain talking to their children about their diagnosis (Phillips et al., 2015) and impending death (Bylund-Grenklo et al., 2015), through to the bereavement phase (Zaider et al., 2015)—by way of demonstrating parenting concerns for individual families are likely to morph along the IESC phase, placing importance on offering responsive and tailored parenting supportive care to individual families throughout the palliative care treatment phase to help reduce patient and family distress and promote family functioning.

The considerable prevalence, diversity, pressing nature of parenting issues unique to the IESC phase (Park et al., 2019; Zaider, et al., 2015) was strongly illuminated. Parenting-related stressors were of primary concern to patients and co-parents and presented as past-, present- and future-based. Accounts of historical grief and trauma resurfaced for some patients included child suicides, estranged child-parent relationships, and placement in out of home care, highlighting that patients' parental grief may extend beyond the commonly reported anticipatory grief experienced by parents, such as leaving a child behind and missing their developmental milestones (Semple et al., 2010). Immediate and future concerns were broader in nature ranging from practical to spiritual. Parent participants raised unaddressed parenting issues that reflected medical, technological and communication advancements and included—ensuring the biological safety of their children during and post toxic palliative treatment, internet and social media education and supervision (i.e., IESC information) and genetic health education for children—not reported by health professional study participants or widely evidenced in the psychosocial intervention evaluation literature. Health professional perspectives expanded on common practical parenting concerns reported in the research literature (Aamotsmo et al., 2014) to include patients' desire to learn quick and adaptive physical strategies to enable them to continue with affirming parenting roles and responsibilities. These findings speak to the value of an

interdisciplinary approach to sharing the responsibility of parenting supportive care by working collaboratively to comprehensively assess individual families' support needs and the importance of continued training and education to ensure parenting supportive care and educational resources are attuned to the evolving parenting landscape, and is proactive, responsive and trauma-informed.

Psychosocial context of parenting

Outcomes from the clinical data mining study found that clinical (i.e., cancer type and IESC diagnosis within one month of initial cancer diagnosis) and sociodemographic factors were unrelated to whether patients received increased hospital-based parenting supportive care at any point during their palliative treatment. This was an unanticipated finding given terminally ill patients facing additional stressors, such as single-parenting families and young parents were reported as being more visible by practitioners interviewed in this project. Possible methodological issues, such as the uniqueness of the sample and power to detect the differences could be attributed to this result. Another possible explanation could be that the parenting concerns are possibly more universally experienced across this patient population. Drilling down to specific parenting-related issues—however—multiple clinical, sociodemographic and psychosocial factors were associated with increased parenting supportive care provision. Key clinical and sociodemographic factors included timing of IESC diagnosis from initial cancer diagnosis, age group of parents, number and age group of the children and single-parenting status of patients were indicated. Various psychosocial issues—patient distress, co-parent concerns, end-of-life care and bereavement, and familial-based stressors—were also related to patients receiving increased supportive care for specific parenting issues. While there are likely numerous plausible theories for these results, such as patients and co-parents being observed by healthcare practitioners as emotionally distressed due to family-based and end-of-life stressors and consequently more likely to be offered supportive care, no conclusions can be drawn due to the limitations of this study.

Inhestern, Haller et al. (2016) argue that all patients and their families facing cancer should be offered family-focused psychosocial supportive care regularly to prevent the development of high levels of parenting concerns. Given the reported increased risk of psychosocial distress on families due to the high burden of parenting and psychosocial stressors that can occur during the palliative stage (Hailey et al., 2018)—including trauma and family violence which are largely unreferenced in palliative parental cancer intervention studies—offering of family-focused parenting support as part of routine care is evermore so warranted for this patient subgroup, and could help facilitate the use of support (Inhestern et al., 2016). While in Australia it is not legislated practice for this patient subgroup to be offered family-focused supportive care when accessing hospital healthcare services, international palliative and cancer care standards and cancer care practice guidelines (NICE, 2004; NBCC & NCCI, 2003) recommend family-inclusive supportive care. In Victoria, one key area of health policy reform has focused on building the capacity of the health system to identify and proactively respond to the supportive care needs of persons with cancer, including those requiring palliative care (DHV, 2019b).

Not all patients and their families will require health professional support in conjunction with their hospital-based treatment. However, from a family resilience framework perspective (Walsh, 2003b), offering families equitable access to holistic, trauma-informed parenting supportive care can provide families with an opportunity to strengthen their resources to optimise individual and family adaptation, family relationships and family functioning. Anticipating the death of a parent is a family crisis from any perspectives and requires a healthcare response (Bugge et al., 2009). As exemplified by this study findings, facing parental death is not a simple short-term event but more so a complex set of shifting conditions with a historical and future course (Rutter, 1987).

Summary and discussion: Parenting supportive care practice findings

From the evidence presented in this thesis it is concluded that parenting supportive care was utilised by a diverse range of patients and their families as part of routine hospital-

based palliative treatment to address a wide variety of parenting issues beyond the realm of seeking support with talking to their children. When parenting issues came to the attention of a treating health professional an interdisciplinary response usually followed. Perspectives shared by key stakeholders—multidisciplinary healthcare professionals and patients and co-parents—indicated that delivery of optimal parenting supportive care practice was challenging and that organisation-, health professional- and parent-based factors influenced service implementation and utilisation.

Practice approach

Health and disease are determined not only by biological factors but psychological, behaviour and social factors (IOM 2001; IOM 2008), necessitating holistic psychosocial services that address the whole person. Overall, a service response that was patient-centred, family-focused, holistic and sensitive and delivered throughout the palliative treatment phase into the bereavement period using an interdisciplinary care approach was considered as constituting optimal parenting supportive care practice. This viewpoint was shared by both multidisciplinary healthcare practitioners and parents. Patient-centred care was premised on support being delivered with empathy (Santana et al., 2018), parent-practitioner trust and rapport, parental control over decision-making regarding service engagement and intervention timing and type (Newman & Medeiros, 2015). Importance was placed on support being responsive to patients' and their families' preferences, needs and values as is commended by the Institute for Patient- and Family-Centered Care (2017). Both patients and health professionals placed high value on authentic parent—practitioner communication for developing rapport and trust; health professionals further stipulated how rapport was best developed over time. However, if taking the perspective of parents that the quality of parent—practitioner engagement is the crucial factor, this suggests that meaningful and beneficial parenting interventions are likely possible through brief interventions.

Parents' desire to have control over what supportive care interventions they and their family engaged with was prominently voiced. They placed the onus on health professionals to initiate parenting-based discussions including proposing support but

wanted the power and autonomy to accept or decline assistance offered without affecting future service offers and interventions. Parents indicated various rationale for wanting control—including the uncertainty of their disease trajectory, ability to determine what support best suited their own and their children's needs and the format and timing for this, as well as their emotional, cognitive, and physical capacity to engage. Parents' desire for parenting-related services can change over time. Therefore, providing parents the option to periodically review what supports they want is probably warranted; the message for health professionals being—"Ask, but not just once". A crucial aspect of asking, is ensuring that parents first understand what is being offered, so they can make an informed decision regarding whether or not they require it. These findings draw attention to the importance of service responses being undertaken in partnership with patients and their families facing IESC; a partnership whereby decision-making is openly discussed and negotiated to ensure supportive care remains patient-centred.

The study results demonstrated that parenting supportive care delivered using a family-focused approach was viewed by stakeholders as quality care. From a systems perspective (King & Quill, 2006; Mitschke, 2008), these findings are in accord with the strong and mounting evidence that terminal parental cancer affects family members (Zaider et al., 2015) and family functioning (Kühne et al., 2013). International palliative and cancer care practice guidelines (NICE, 2004; NBCC & NCCI, 2003) explicitly recommend for the supportive care needs of family members to be addressed and for the recognition of patients' parental role. Divergent perspectives between practitioners and parents regarding what constitutes family-focused support were revealed in this study. Parents' perceived that family-focused support includes child-centred interventions whereas practitioner viewpoints differed across professional disciplines, warranting its need through challenges experienced accessing appropriate community child-centred support service. Practitioners from disciplines such as social work, whose practice has historically engaged in family-centred interventions (Loscalzo, Clark & Bultz, 2015) shared parents' viewpoints; however, other healthcare disciplines positioned family-focused interventions as working more so with the patient, co-parents or the family unit as a whole. In the parental cancer intervention field, it is

generally considered that child-centred supportive care requires a specialised skillset (Fearnley, 2010). Evidence indicates that with targeted education and training, multidisciplinary healthcare professionals can readily acquire the necessary knowledge, skills and confidence for child-inclusive family-focused support practice (Bugge et al., 2009; Grant, Sangha, Lister & Wiseman, 2016; McGillicuddy, Gold & Lowe, 2015; Turner et al., 2007b) and potentially motivate and engage staff to provide supportive care (Bugge et al., 2008; Romer et al., 2007).

Parenting and psychosocial interventions evidenced in this study spanned several domains including: physical, emotional, psychological, social-cultural and spiritual. For many, the experience of facing death or having a loved one with a life-threatening illness is regarded as the most significant trauma irrespective of other life events (Piertzak, Goldstein, Southwick & Grant, 2012). The challenges however for many families may be compounded by other stressors. As evidenced in this research project parents presenting for hospital-based palliative cancer care may be dealing with complex psychosocial situations—such as mental health, cultural and trauma-related vulnerabilities. These data demonstrate the high relevance for a holistic and sensitive family-focused approach to parenting supportive care that is trauma-informed—a unique finding to this study. Delivering trauma-informed care comprises providing effective, compassionate and culturally sensitive care including routine screening for patient's trauma histories (Vu, Rothman, Battaglia & Bair-Merritt, 2015) and interventions that prevent retraumatisation and promote trust, safety and patient empowerment (Ganzel, 2018; Lawson et al., 2018).

Combined results of the three studies revealed the central role that the interdisciplinary health professional team had in implementing parenting-related supportive care services including but not limited to parenting status screening, parenting needs assessment, referrals and interventions. From parent perspectives, the interdisciplinary approach to parenting supportive care was experienced as favourable; it provided opportunities for parents to exercise their preferences with whom they engaged with; individual health professional disciplines offered varied perspectives, strategies and informational resources to parents helpful in addressing their concerns; it reduced the

need to repeat sensitive family-based information to healthcare team members and helped facilitate a streamlined integration back into the community post hospitalisation.

Medical, nursing and allied healthcare disciplines offered parenting-related support alongside more specialised practitioners such as social workers, commonly recognised as having expertise in delivering family-focused therapeutic and practical interventions. Collaborative communication was considered by practitioners and parents as key to effective interdisciplinary parenting-focused care provision; when shortfalls occurred, practitioners and parents concurred that patient's parenting support needs could remain unmet. While an interdisciplinary approach to treatment has been a feature of specialised palliative care (Crawford & Price, 2003) and hospital-based cancer care (Cancer Australia, 2019) and is recognised as integral for achieving optimal patient outcomes (IOM, 2001), little attention has been given to its specific role in delivering hospital-based parenting supportive care. Hospital systems comprise healthcare disciplines often organised independently of each other, with limited or no coordination around delivering integrated psychosocial supportive care to patients from active cancer care to palliative care (Fann et al., 2012). The author is not aware of any other research investigating parenting supportive care to this patient subgroup where services are integrated into routine interdisciplinary hospital healthcare. This study revealed there were multiple disciplines providing parenting supportive care, however no single discipline took a leadership role. Several leadership models exist including the interdisciplinary staff leadership model for patient-centred care *Leading by Learning and Inspiration* (Loscalzo et al., 2015) for such purposes. The social work discipline may be well positioned to facilitate a collaborative system of interprofessional and interorganisational partnerships needed to deliver quality parenting supportive care as part of routine hospital healthcare.

Organisation factors: Processes and procedures

Visibility of parents and their parenting concerns

This dissertation identified that parenting support needs were not always readily visible to the interdisciplinary healthcare team and, in some cases, the patients and/or co-parents themselves. Various organisation, health professional and parent-based factors were identified as contributing to this result.

An anticipated organisation-based barrier was revealed during the phase I study recruitment period. Identification of patients parenting young families was difficult as parenting status and children's age data were not systematically reported in patients' medical records. Where it was recorded, the information was often not specific or easily locatable. In Australia, cancer staging (when care transitions from curative to noncurative treatment) and parental status data is not required for local or national healthcare reporting purposes, thus contributing to the challenges. The data from patients' medical records indicated the absence of a defined clinical pathway with ad hoc parental status screening and recording of family-based data, which was subsequently confirmed through the health professional and parent interviews. Systematically identifying patients' parenting status when they present to hospital for inpatient or outpatient palliative-based cancer treatment would appear to be one of the initial and logical processes in a formalised clinical pathway that could help facilitate equitable access of parenting supportive care to this at-risk patient subgroup. Data from this thesis has illustrated that patients who are parenting young families can present with very diverse clinical, sociodemographic and psychosocial profiles (Chapter 3) and point to the potential limitation of relying on factors such as age or sex to identify which patients are likely to have primary parenting responsibility for children aged up to 18 years old; parental cancer literature often refers to patients raising young children as 'young parents' (Bultman et al., 2014; Kuuppelomäki & Lauri, 1998; Werner-Lin & Biank, 2009) and 'mothers' (O'Neill et al., 2018). Parents in this study—biological, nonbiological and extended family members—were aged up to 75 years old and comprised a relatively equal portion of males and females. Directly and routinely

enquiring with all patients diagnosed with IESC about their parenting status irrespective of their clinical or sociodemographic background could be a more reliable method for accurately identifying which patients are parents of minor children. Those identified could then be asked to complete a comprehensive parenting needs assessment, as part of a psychosocial assessment. The parenting assessment could include a review the family system's strengths and needs—including children's supportive care needs and accessible informal and formal support systems and illustrated as a genogram (Behar et al., 2015) so it is readily viewable by the care team. Medical and nursing professionals were identified as the first healthcare team members to record basic family data from patients presenting to inpatient or outpatient services; and therefore, may potentially be well positioned to take a prominent role in routinising parenting status screening.

Findings of particular importance were parent narratives and clinical data that confirmed parents' general receptiveness to the notion of being routinely screened for parenting concerns throughout the IESC treatment phase. There were no unanimous preferences stated by parents regarding who from the hospital healthcare team should conduct the screening or when; sensitive inquiry was the primary request. Interview data from study phases II and III (Chapters 4 & 5) indicated the potential importance of formalising the process of parenting needs assessment given healthcare practitioners were not always cognisant of patients' and co-parents' supportive care needs and did not routinely undertake an assessment to investigate. Some practitioners waited for patients to initiate parenting-related discussions while others reported organisation factors such as clinical pressures, limited staffing and lack of resources as reasons for not routinely assessment parenting needs. Parents, on the other hand, were sometimes unsure or lacked insight into their own support needs and that of their children, findings similar to studies focusing on parents with metastatic cancer (Kroll et al., 1998; Bugge et al., 2009). Other parents were unaware of the availability of parenting support in the hospital setting or how to access it, impacting on their support-seeking efforts; themes similarly reported in a population-based psychosocial support study involving parents with varying cancer staging (Ernst et al., 2013) and qualitative study involving parents with advanced cancer (Turner et al., 2007a).

Disparate views and limited communication between parents about their children's understanding of the situation, parenting issues and support needs also appeared to influence what issues came to the attention of health professionals. Talking with a trusted health professional was reported by some parents as helpful for uncovering their parenting 'blind spots' and articulating and deciding what assistance could be beneficial to themselves or their children. Existing research findings conducted with parents with IESC and metastatic cancer indicated a reluctance to discuss parenting issues if health professionals did not ask them (Bugge et al., 2009; Turner et al., 2007a). Therefore, it may be beneficial to parents for health professionals to assume responsibility for initiating parenting-related discussions including needs assessment. That said, it may not be a simple task to ask a parent what support they want by ticking off a 'problems checklist'. Rather, an exploratory, interactional process may be needed that is accompanied for example, by a validated and available assessment tool such as the *Parenting Concerns Questionnaire* (Muriel et al., 2012).

Resources and time

Structural factors—resources and time—were perceived by multidisciplinary practitioners and parents as noticeably influencing optimal hospital-based parenting support provision. Viewpoints converged on human resource shortfalls and limited access to parenting resources within both the hospital and community settings. Clinical time pressures, inadequate funding and ethical issues faced by practitioners of offering undeliverable services were solely raised by health professionals. These themes echo the barriers referenced in Australian and international cancer psychosocial screening and intervention literature—the perceived time-consuming nature of unpacking parenting issues (Rauch & Moore, 2010), clinical time pressures (Dencker et al., 2017; Dilworth, Higgins, Parker, Kelly & Turner, 2014), staffing shortages and limited parenting resources (Turner et al., 2007b) through to broader-based commentary investigating barriers to incorporating psychosocial supportive care into routine care (Ristevski et al., 2011). In consideration of these challenges, the widely recognised impact palliative-stage cancer can have on parents' and their families' current and future wellbeing and benefits of family-focused supportive care, it appears an approach using existing financial and

time resources is likely necessary. Patients and co-parents shared how time spent by health professionals had an immediate beneficial impact on their distress and their family functioning; face-to-face hospital-based parenting interventions helped free up their limited time and energy for their children otherwise expended on problem-solving and/or self-sourcing parenting material or external services. Parents expressed mixed responses regarding self-help strategies such as utilising internet-based parenting support and resources; citing lack of time as a barrier.

Together, these findings shed light on another aspect of how hospital-based parenting supportive care is valued by parents and provide further impetus for exploring how the parenting supportive care needs of these vulnerable families can be effectively and efficiently addressed within a time- and financially-pressured environment. While there remains much to be understood about which parenting interventions would best assist parents (Steiner, Shlonsky & Joubert, 2017), the practice efficiencies that may result through improved staff confidence and competence from targeted clinician training and education, as well as utilisation of existing and available international parenting intervention resources, are just two of the many possible ways that may prove helpful to providing quality supportive care. Addressing structural barriers may also result in indirectly shifting psychological and emotional-based barriers experienced by health professionals (Dencker et al., 2017).

Hospital environment

Practitioners, patients and co-parents conceded that having a safe, family-friendly, culturally and spiritually sensitive hospital environment that offered safe and private therapeutic spaces created a conducive environment for families facing terminal cancer. The importance of a patient-centred hospital environment that serves to augment healing, health and dying and promotes a family-friendly healthcare experience is increasingly recognised as important to patient and family wellbeing (Bromley, 2012; Franck, Ferguson, Fryda & Rubin, 2015). Health professionals described how the lack of privacy, chaos and noise and limited child-friendly spaces hindered parenting supportive care practice. Both parents and practitioners shared the view that in addition to structural factors, having a family-focused, cultural, spiritual and trauma sensitive

ethos led to helpful and therapeutic supportive care—from the time of initial IESC diagnosis through to the bereavement phase where parental death had occurred in the hospital. Key areas for improvement elicited by parents and practitioners, in addition to improved physical environments, focused on the need for increased use of professional interpreters instead of child and adult family members and cultural workers. Additionally, a parent-proposed service enhancement included preferential outpatient appointments for palliative-stage patients perceived to be at additional risk of distress, such as those caring for children with disabilities.

These findings reveal that a holistic and family-focused safe environment was valued by patients and their families during the palliative treatment, death and bereavement phases, and also viewed by health professionals to be beneficial to families. The acute hospital setting appeared to be conceived as a place of healing, significant life transitions and precious family time; not merely a functional place to receive biomedical healthcare. Health professionals appeared cognisant of the significance of safe and nurturing therapeutic spaces in promoting quality family-friendly healthcare experiences. Together, viewpoints shared build on current hospital healthcare family-focused experience research by highlighting the preferences of these families, examples of how hospital environments—functional space and culture—can influence quality family-focused parenting supportive care provision to these vulnerable families and potential areas for strengthening hospital-based care.

Multidisciplinary health professional factors influencing practice

Three key areas were identified at the health professional level as influencing optimal parenting practice: training, education and skills; actual and perceived scope of practice; and, support and supervision. Similar themes are present in studies reviewing psychosocial care for adults with cancer (Dilworth et al., 2014) and family-focused psychosocial interventions for parents with cancer (Inhestern et al., 2016); no studies were identified reviewing practitioners' or parents' perspectives of hospital-based parenting supportive care practice for families facing palliative-stage parental cancer.

Training and education

This thesis found that parenting supportive care delivery operating from an interdisciplinary care model facilitated both purposeful and incidental cross-disciplinary learning opportunities. Indications from practitioners and parents interviewed, however, suggested that most healthcare disciplines could benefit from targeted ongoing skills training and education to increase confidence and competence with screening, assessing and delivering parenting support that was family-focused, culturally sensitive and trauma-informed. Parents recounted some barriers to optimal parenting support provision relating to the quality of health professionals' communication, confidence, and lack of awareness of patients' and co-parents' preferences regarding delivery of parenting care. Evaluation studies of education and skills training programs for health professionals working with parents with cancer (Grant et al., 2016) and metastatic cancer (Turner et al., 2008) have found participants reported increased confidence and skills in discussing parenting matters with patients and exploring family-related concerns, guiding parent-child communication about parental illness and treatment and providing informational resources.

Scope of practice

This study found that health professionals' perceptions of their discipline's scope of practice influenced their prioritisation of enquiring about and addressing patients' parenting support needs. Parenting issues were not equally viewed as a clinical priority across the multidisciplinary team despite practitioners' recognition that parenting was a primary concern for patients facing terminal cancer. Study evidence illustrated how parenting supportive practice occurred in a tiered way—with some practitioners such as social workers providing support and interventions across a wide range of parenting-related concerns while others had more specialised engagement, such as physical-based interventions. While parenting supportive care was perceived by some practitioner participants as not being within their professional disciplines' scope of practice, conducting a retrospective clinical audit of the documented service response (Chapter 3) demonstrated that in practice an interdisciplinary response often occurs when

parenting concerns are made visible. Delivering health professional education focused on interdisciplinary parenting supportive care, highlighting possible individual discipline and team-based responses, might support practitioners to re-examine their viewpoints and level of engagement with parenting-related practices.

Professional support and supervision

Health professionals professed to feeling emotionally and psychologically taxed at times, stating clinical competency did not alleviate feelings of distress encountered through work with these families and witnessing patients' inequitable access to resources. End-of-life care is recognised as challenging and unmanaged stress understood to have the capacity to erode empathy and negatively impact on patient and family outcomes (DHV, 2019a). While clinical supervision is increasingly recognised as a core component of professional support for many disciplines, it is not often a formalised and structured practice. Informal collegiate support and self-care strategies are more often relied upon. A recent Australia-wide study showed that a majority of medical and nursing professional participants working in palliative care had not received self-care training (Mills, Wand & Fraser, 2017) with a sizable percentage found to rarely engage in self-care practices. Given the potential benefits to self-awareness, wellbeing, professionalism a more formalised approach to supervision and self-care training may be valued.

Patient and co-parent factors influencing service utilisation

Only a handful of studies have investigated patient and co-parent factors influencing healthcare-based parenting supportive care interventions tailored for families facing terminal cancer, inclusive of the ill parent. Those that have been conducted suggest that in order for parents to utilise parenting support services, they need to understand there is a need for assistance for themselves, their children and their family (Bugge et al., 2009; Inhestern et al., 2016; Thastum et al., 2006). For example, if parents were aware of changing behaviours in their children that they were unsure how to respond to, they were more likely to seek formal assistance for themselves and their children. Results reported in this dissertation suggest similar themes that align with this perspective.

Parents' strong desire to protect their children and to be good parents appeared to influence patients' and co-parents' engagement with parenting supportive care. While parents drew on their own and the families' strengths and resiliency to cope, and exhibited resourcefulness by mobilising additional informal and/or community assistance, health professional reports indicated parents were generally receptive to health professional guidance when they were uncertain how best to support their children or unaware of support service availability.

Parent-related factors considered to potentially hinder hospital-based parenting support utilisation were multidimensional. Influencing aspects included patients' state of illness; parents' emotional and psychological readiness to discuss parenting-related end-of-life issues and death; personality, time availability, non-English speaking status, feelings of safety, parent and/or family held beliefs that talking about death and dying was a taboo; and protective behaviours of parents, shielding themselves and their children when feeling overwhelmed by support services. For some families, parents' divergent views about openly discussing disease progression and parenting matters impacted on service engagement.

These experiences, preferences and perceptions offer a nuanced picture in that, while health professionals may perceive services they have to offer as potentially beneficial to patients' and families' by way of building on parents' strengths, resiliency and parenting confidence and competence, parents may experience ambivalence with accessing parenting support at any point for a range of reasons. The literature describing the dynamic journey of parenting during palliative-stage cancer together with these findings suggest the importance of evidence-informed hospital-based parenting support being delivered sensitively and respectful of individual family's needs. As such, there appears sufficient evidence to promote for multidisciplinary health professionals across the hospital system to be appropriately trained to respond to parents' and families' parenting support needs when issues arise.

Unexpected findings: Diagnosis, prognosis and parenthood

This research project has centred investigations on parenting supportive care provision for patients diagnosed with IESC and their families. Exploring patients', co-parents' and multidisciplinary health professionals' experiences and viewpoints on parenting support service provision the issues of IESC diagnosis and prognosis communication repeatedly surfaced. It would be remiss not to share an overview of diagnosis/prognosis parent—health professional communication themes as they further contextualise patients' and co-parents' parenting challenges, such as how they discuss prognosis with their children and the pivotal role hospital healthcare professionals have in providing quality parenting-related supportive care with supporting (Hailey et al., 2018).

Parents experienced differing levels of comfort discussing their prognosis due to their own fear, protectiveness of their spouse and children, and health professionals' execution of the news. Some parents expressed the high importance of receiving a prognosis regardless of the discomfort it caused stating the information helped with parenting tasks such as future planning (Bugge et al., 2009); other parents were less keen to have a defined timeline while they were functional and hope remained a possibility; and some spoke openly with their children but others did not. Health professionals detailed multidisciplinary team-based strategies they used to sensitively engage with patients and their families to discuss diagnosis, prognosis, and death, highlighting difficulties they encountered. Ineffective parent—health professional diagnosis and prognosis communication is a topical but longstanding reported phenomenon in healthcare practice (Fearnley, 2010; MacPherson, 2005).

The importance of open communication about diagnosis and prognosis within families is widely reported (Bylund-Grenklo et al., 2015; Hailey et al., 2018). Recent studies show how extensive parent—child communication about their advanced cancer and prognosis can heighten parents' generalised anxiety (Hailey et al., 2016). The relevance of these findings are that they confirm some of the sensitivities patients have with acknowledging the likelihood of early mortality and sharing such news with their children (Hailey et al., 2018; Yoshida et al., 2010). It confirms the difficult tensions within which health professionals must operate when communicating the incurability

of the cancer and prognosis—including the challenge of supporting patients to concurrently manage with their own reactions and responses and support needs of their children (MacPherson, 2005) as well as their own discomfort (Waldrop et al., 2015) and confidence in managing the conversation skilfully (Anderson, Kools & Lyndon, 2013). Healthcare practitioners need ongoing training and professional supervision to ensure they are well equipped to communicate competently with parents and their families about these life-changing matters (Fearnley et al., 2017).

Strengths and limitations

This section will discuss some of the key strengths and limitations of this mixed method PhD thesis in addition to those covered in Chapters 3–5, with particular focus on research design, participant sampling and recruitment and participant voices represented and those not, to ensure the offerings of this study can best be understood and contextualised.

Research design and method

One of the strengths of this dissertation was the mixed methods sequential design (Creswell, 2015). The first phase involved the nonintrusive method of retrospectively data mining the medical records of a diverse group of patients diagnosed with IESC for clinical, sociodemographic and psychosocial service provision data. It facilitated an examination of the documented clinical, sociodemographic and psychosocial profile of terminally ill cancer patients raising minor children and access hospital-based treatment. Data revealed the types of parenting issues that came to the attention of the treating team including service responses in particular, which patients did and did not access hospital-based parenting supportive care. Data were mined from records reported over the IESC treatment phase, enabling a longitudinal perspective of parenting and psychosocial service utilisation to be obtained, and opportunities to explore which health professional disciplines were involved in supportive care provision offered as part of routine hospital healthcare.

The Phase I study findings, together with theories drawn from the literature, informed the research questions for the in-depth qualitative prospective Phase II and Phase III studies. These qualitative studies explored in depth patients' and co-parents parenting concerns and hospital-based supportive care service responses, and unmet support needs and service improvement from the perspectives of key stakeholders—multidisciplinary healthcare professionals and patients with IESC and their co-parents who are raising minor children. These perspectives are largely absent from the palliative-stage parental cancer hospital-based intervention literature. These data addressed a substantial research gap as the few previous parenting-focused intervention studies involving this patient subgroup have largely focused on evaluating parenting programs not integrated into routine interdisciplinary hospital healthcare but more so offered as an adjunct (Bugge et al., 2009); few studies have explored parenting supportive care service provision across the IESC phase.

Nature of the sample

Overall, the sampling methods for the project were selected so they strictly aligned with a primary ethical goal of being minimally intrusive of the patient and co-parent population due to their sensitive circumstances and potentially distressing nature of the topic. Several limitations were associated with sampling and recruitment. Participants identified for the Phase I clinical data mining study were convenience samples, not random, of moderate size ($N = 74$) and were obtained from a single-site. The sample is nonrepresentative and therefore findings may not be generalisable to the broader population of IESC's or hospitals. Recruitment relied on the clear documentation of a primary inclusion criteria: being a parent of minor children. Given that parenting status was not routinely or clearly recorded, patients who were parents of minor children may have been omitted. Because the utilisation of parent-related services would indicate parenthood in the file, the number of patients who did not receive parenting supportive care is likely to be underestimated.

Participation in the convenience sample focus groups and interviews was voluntary, thus they may also have limited generalisability to the broader population (Robinson,

2014). To counter the commonly underrepresentation of parent subgroups such as, fathers, single-parents, parents from culturally and linguistically diverse (CALD) backgrounds and those with a lower socio-economic status—utilisation of convenience sampling methodology provided some level of control with recruiting a reasonably heterogeneous group of patients with varying cancer types and time since IESC diagnosis, sex, age, child age, family structure and country of birth.

A strength of this study was the inclusion of multidisciplinary health professional perspectives inclusive of social work, clinical psychology, pastoral care, Australian Indigenous cultural care team, physiotherapy and occupational therapy—in addition to medical and nursing—all disciplines routinely engaging with these patients as part of hospital-based palliative care. As endorsed by IOM (2001; 2008), palliative psychosocial supportive care is an important component of cancer and palliative healthcare and the responsibility of the multidisciplinary team. It is acknowledged that the sample of healthcare practitioners recruited however was not fully representative of the professional workforce providing clinical care to hospital patients; few participants were inexperienced which may have influenced the types of service delivery barriers experienced such as education and skills training that are more likely to be reported by less experienced practitioners (Fearnley, 2010).

Recruitment of patients for interviews relied on frontline health professionals involved in patients' outpatient and inpatient care. It is unknown how many engaged in gatekeeping practices commonly reported within the palliative care research literature (Hanson et al., 2014; White, Gilshenan & Hardy, 2008). Several measures were undertaken to address gatekeeping actions to promote patients' right to decide to participate in the study, with full consideration given to patients' wellbeing and capacity to give informed consent. They included providing repeated verbal and written information to recruiting health professionals regarding the aims, objectives, participant inclusion criteria, and anticipated beneficial patient outcomes; delivering education sessions via different individual and team-based forums in the inpatient and outpatient settings; engaging the support of several key respected medical practitioners working with parents receiving cancer and palliative care across the inpatient and

outpatient settings; engaging various multidisciplinary staff in identifying potential candidates and asking them to discuss their suitability with the patient's treating medical practitioner; maintaining a physical presence across multiple inpatient and outpatient clinical areas for six weeks to reduce any opportunity to use 'researcher unavailability' as a rationale for not recruiting patients who may want to be interviewed immediately following an enquiry of their interest in participating in the study; and using this presence to reduce the steps in the recruitment process, such as emailing or phoning the researcher with referrals.

Co-parent sample size was small as several male co-parents of the eight patients declined to participate; attempts to address this were made by offering co-parents the power to choose the interview day and time and use of professional interpreter for those non-English speaking; follow-up calls were also made with patient consent. Difficulties recruiting non-English speaking participants (Newington & Melcalfe, 2014) and males (Tully et al., 2018) were anticipated as it is widely reported across parenting intervention research literature.

Data collection

A strength of all three study phases was the consideration given to the trauma, cultural and spiritual domains of patients' and families' experiences in an attempt to capture data essential for informing holistic practice. The phase I study clinical data mining tool (Appendix 1) facilitated the collection of a wide variety of psychosocial issues documented in patients' medical records including these issues relatively unexplored in the context of hospital-based parenting supportive care intervention studies. Further, first-hand experiences of patients and co-parents were captured through the phase III in-depth interviews. The phase II study was specifically designed to capture the perspectives of hospital healthcare team members often significantly involved in addressing such supportive care needs, such as social work, clinical psychology, pastoral care and Australian Indigenous cultural workers.

Analysis

As outlined in Chapter 3, psychosocial and parenting issue data were initially coded using the clinical data mining audit tool and what emerged from the data and then reviewed to combine similar themes. The data were then categorised into broader categories to conduct the analysis. Further refinement of the individual psychosocial categories, such as family-based issues would have provided more specific data.

Voices

Inclusion of both patient and co-parent experiences and perspectives of parenting concerns and hospital-based supportive care experiences and perspectives of a diverse range of parents was a strength and ethical hallmark of this study. To date, the perspectives of this patient populations are particularly absent serving to perpetuate the gaps in knowledge base of this at-risk group. Hanson et al. (2014) identified how conducting research with vulnerable patient populations, such as those with terminal illness, is often difficult due to barriers including finding eligible patients that meet specific inclusion criteria, patient illness fluctuation, gatekeeping by physicians and caregivers, demands of hospital settings and limited time resources. Moral and ethical concerns relating to the risk of increasing participants' distress is also widely reported (de Raeve, 1994; Duke & Bennett, 2010; Hanson et al., 2014). Evidence from this study however revealed parents facing IESC with young families were prepared to participate in research and valued the experience, expressing gratitude for being offered the opportunity to contribute to the parenting supportive care evidence-base and to help improve support services for future families facing similar circumstances. Equal to other vulnerable patients they deserve evidence-informed supportive care, which requires participation in research projects such as this.

The complexity and multidimensional nature of parenting and psychosocial challenges and hospital-based supportive care needs were communicated directly via in-depth patient interviews (Chapter 5) and indirectly through documented and reported accounts by health professionals (Chapters 3 & 4). The direct voice of these patients and co-parents, often excluded from parenting supportive care intervention research, was a

fundamental strength of this study; they shared heartfelt and sensitive personal and family experiences with great sincerity and trust; exposing their past and current vulnerabilities. Their insights, knowledge, experiences and perceptions are all useful in developing and implementing quality patient-centred care responsive to the parenting support needs of these families; notably, it made visible patients' parent identity that is often ignored in the context of healthcare yet understood to have a significant impact on patients' and families' wellbeing, their medical treatment decision-making, quality of life, and end-of-life planning (Nilsson et al., 2009).

A primary limitation however was the exclusion of children's voices, whose perspectives of hospital-based parenting supportive care have yet to be explored in any depth. Recent research including children's perspectives has centred on their experiences of family-focused interventions (Bugge et al., 2008) and communications regarding prognosis, disease progression and end-of-life issues (Alvariza et al., 2016; Turner et al., 2017a). Children were excluded primarily due to anticipated difficulties and delays with the ethics approval processes. Data regarding children's support needs and engagement with hospital-based supportive care however were secondarily voiced in all three study phases by parents and health professionals (Chapters 3-5). Future research that includes the direct viewpoints of children would be beneficial for strengthening quality family-focused parenting supportive care in the hospital setting.

Benefits of research

Aside from the ethical considerations associated with undertaking sensitive research (Jubb, 2002), the intention driving the research to improve services and the potential benefits to participants were important factors mindfully revisited throughout the project. Often the potential benefits to research participants are only loosely considered, underrated or not considered. That said, research studies in palliative care are highlighting that, for some participants, the interview process can be a therapeutic and empowering experience (Gysels, Shipman & Higginson, 2008). This study purposely promoted the rights of terminally ill parents and their co-parents by offering them the choice to engage in research directly impacting on them. Patients and co-

parent participants interviewed (Chapter 5) reported beneficial outcomes including feeling valued by being provided an opportunity to voice their viewpoints and share their first-hand experience of parenting minor children in the face of palliative-stage cancer. They also expressed appreciation for the opportunity to contribute to the dialogue about which types of hospital health professional assistance are helpful in supporting them during this difficult time.

> *You're so welcome. I hope that I've helped in some way [improving future supportive care to families by sharing experiences and supportive care service preferences]. Definitely an area that should be looked at.*
>
> (Patient, co-parenting)

The interview forum appeared to serve as a safe space for parents to disclose parenting and service experiences not previously shared, acknowledged and validated. For parents with unmet parenting support and healthcare service navigation needs, a referral to the healthcare team was made with the participants' consent.

Participation in the focus group afforded multidisciplinary health professional participants unpressured reflective time away from their clinical duties to explore and develop a greater understanding of patients' parenting issues and the service responses currently undertaken by individuals and healthcare teams within their workplace. Importantly, discussion helped to collaboratively identify factors perceived to assist and hinder quality supportive care to parents with IESC, bringing to the fore parenting concerns of patients, service gaps and strategies employed to counter these, and supervision and self-care.

At a hospital systems level, the data can be used to inform hospital-based policy and procedures and practice guidelines for those working with these patients and their families. It may generate education and training initiatives for hospital-based multidisciplinary health professionals including hospital management. Dissemination could also engender future research initiatives including quality improvement projects

or larger hospital-wide projects with the view of enhancing holistic and responsive family-focused parenting supportive care practice.

Through dissemination (see Appendix 9), this research can be of benefit to other patients and their families who are experiencing parental IESC by raising their awareness that parenting concerns and supportive care is a topic that can be discussed with a member of their hospital multidisciplinary team as part of healthcare treatment. It may serve to raise open discussion within families and across community groups about parenting in the context of dying—a topic that remains challenging and is often a taboo.

Practice implications and future directions

This thesis has shown several possibilities for service improvement at the systemic, organisation and health professional levels.

A consideration of an addendum to the current *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer* (NBCC & NCCI, 2003) is warranted to provide multidisciplinary health professionals evidence-informed guidelines for conducting parenting supportive care during the palliative-stage of cancer care as there appears limited attention to healthcare responses to families' parenting-related supportive care concerns. Another consideration is amendment to supportive care screening checklists to include an open question asking parenting status details (e.g. number of dependent children and age) where not included, and for screening guidelines to include referral instructions where parenting issues arise as a course of inquiry in accord with a proactive approach.

In Chapters 3-5, it was revealed how having no defined and systemised clinical pathway for parenting supportive care may contribute to patients and their families missing out on needed support and sustain inequities. Development of a clinical pathway and routinely screening patients' parenting status and assessing parenting-related support needs during the palliative-stage of cancer care treatment are several avenues identified that could help realise a routinised approach. Development of a clinical pathway from

a family-focused parenting supportive care perspective could complement existing medical-focused clinical pathways. Utilising thesis data and existing parental cancer and palliative care intervention research literature, a patient-centred parenting supportive care clinical pathway is proposed and presented (Figure 1). Clinical tasks outlined in the pathway were purposely not assigned to specific health professional disciplines. Such decisions are best determined by each hospital and their healthcare teams, in collaboration with healthcare consumer representatives.

Figure 1. Clinical pathway: Patient-centred parenting supportive care

To ensure all patients diagnosed with IESC who are raising young families are routinely offered family-focused parenting support as part of their hospital-based healthcare treatment, routinising parenting status screening appears to be one initial step in progressing this. While there are no known best ways or timing for general psychosocial care screening per se of adult patients with cancer (Turner et al., 2017), the brief step of sensitively asking patients on hospital presentation two simple questions about their parenting status, such as the number and age of children and clearly recording the information so it is automatically flagged at the front of and within patient's electronic and/or paper-based medical records (Rauch et al., 2010; Dencker et al., 2017) could be beneficial.

The third area indicated entails the development and implementation of hospital evidence-informed clinical guidelines for assessing parenting supportive care needs, including the use of a validated parenting concerns screening tools, such as *The Parenting Concerns Questionnaire* (Muriel et al., 2012). Evidence from this thesis and research literature highlight the potentially complex nature of parenting and psychosocial issues experienced by families facing terminal cancer and how issues often change over time. These data point to the relevance of repeatedly offering patients, inclusive of co-parents, parenting support needs assessment and responsive interventions along the hospital healthcare journey. While there are likely proactive parents who understand how to activate and navigate the hospital-based supportive care and do so, parents in this study and other studies (Bugge et al., 2009; Turner et al., 2007a) have voiced their general reticence in initiating such discussions or otherwise experience service access challenges, relying on health professionals to take the lead to ensure discussions occur. A review of practice following implementation of the clinical guidelines could be completed as part of a quality improvement project or self-assessment clinical medical record audit routinely undertaken by hospital clinicians in accord with clinical governance requirements.

In the context of providing quality continuity of parenting supportive care as patient care transitions oscillate between home and hospital care during the palliative stage, it is recommended that handover and referral communications are undertaken in

accordance with the Australian national clinical handover standards (Australian Commission on Safety & Quality in Health Care, 2019). As indicated by this study, patients may receive healthcare treatment from a variety of services across their community and effective collaborative communication is key to quality parenting supportive care practice. Further, parental status may weigh into treatment decision-making, and patient and family wellbeing and functioning; all are factors that may influence healthcare access and provision.

If the parenting status screening process is systemised and parenting supportive care is to be embraced there is an ethical responsibility for health professionals to be clinically competent and confident. Recommendations are made for the ongoing education and skill development of multidisciplinary hospital health professionals to strengthen their capacity to provide high quality, evidence-informed, patient-centred, family-focused parenting supportive care to this patient subgroup from the point of screening to bereavement support. Knowledge and skills are best reinforced and consolidated over time (Sutton & Barto, 1998). Health professionals require competence in discussing families' parenting challenges and support needs during palliative-stage cancer care and evidence-informed ways for responding in accordance with their scope of practice. Existing professional training programs could be adapted to create a targeted training package (refer Appendix 8—Training Topics: Interdisciplinary Health Professionals*)*. Examples include a manualised, self-directed training program developed for nurses working with parents with advanced cancer (Turner et al., 2007b), an online *Parenting at a Challenging Time* course tailored for multidisciplinary health professionals that includes parenting at the end-of-life (Marjorie E. Korff PACT Program, 2019). Development of two key practice resources could supplement the training course—a practice prompt card for health professionals with key points for *Supporting Parents and their Families Experiencing End-Stage Cancer* including tips for sensitive engagement and parenting needs assessment questions and a *Parenting Supportive Care Resources Information Sheet* for families. The latter comprising strategies for accessing and navigating hospital-based and community supportive care services, including an explanation of health professional discipline roles, family-focused parenting services and resources (Holland et al., 2018), child-centred services and

educational/informational material; with all shared information being meaningful and relevant to the patients' and families' situations and needs (Epstein & Street, 2011). A recent investigation by Morris, Ohan & Martini (2018) found few parenting support services via Internet searching alone; demonstrating the potential value and importance of providing such interventions.

Addressing localised and organisation and health professional barriers such as legitimisation of time spent addressing parenting-related issues and ethical issues concerning limited resources are topics that could be included. It is recommended that key stakeholders including patients, co-parents, children, multidisciplinary health professionals (including cultural workers) are involved in the development and evaluation of such programs and resources. Collaborative partnerships with external agencies including community-based government and nongovernment cancer and palliative services and consumer groups and universities could help facilitate such initiatives.

Professional supervision and training are key strategies for countering health professionals' exposure to vicarious trauma that occurs while working with families facing terminal parental cancer and developing and accessing health professionals' skills and competencies (Joubert, Hocking & Hampson, 2013); all necessary for facilitating quality compassionate supportive care delivery. This thesis revealed disparities among multidisciplinary healthcare professions' access to regular professional supervision; some practitioners professed to relying on informal ad hoc collegial support. While it is understood that external professional support options may exist (DHV, 2019a), it is proposed that a multidisciplinary resilience-based peer supervision practice group (Kaba & Damaskos, 2015) could provide additional structured support. As an adjunct to this, the development of self-care skills and emotional resilience through training such as *Cultivating Emotional Balance* (Milicevic, Milton & O'Loughlin, 2016) could potentially better equip health professionals. Emotional health is fundamental to the effectiveness of healthcare workers.

To address environmental factors perceived as barriers to optimal parenting supportive care practice, several suggestions are offered. They include creating readily accessible

and family-friendly designed spaces throughout the hospital (outpatient and inpatient areas) such as secure play areas for children in outpatient waiting areas and designated 'family' rooms whereby family members (including children) can seek refuge during hospital visits—as included in many contemporary children's hospitals. The provision of private, quiet and culturally safe therapeutic spaces for individual or family counselling and/or education sessions, as well as family meetings would likely be of benefit. Routinely allocating single-bed hospital rooms for parents facing imminent death would ensure families have privacy during the active palliative phase. In addition to the physical elements, including staff training on the cultural and spiritual perspectives of parenting and death may promote a healing healthcare encounter for patients and their families. To promote a culturally sensitive environment, routine use of professional interpreters instead of family members (including minor-aged children) to reduce the distress on family members may also be of benefit.

Finally, effective leadership is one of the primary requisites needed to successfully implement coordinated and phased organisation and health professional level practice changes to enhance patient care; other aspects include stakeholder engagement—including patients and families, interprofessional collaboration and the delivery of targeted education (Bultz et al., 2011). To facilitate effective change it is suggested health professionals need to have an understanding of the need for change (Al-Abri, 2007), recognise the benefits to themselves and the patient and family, receive positive feedback for implementing the practice changes (Ristevski et al., 2011) and receive visible/tangible managerial support to implement the changes, including clinical time (Dencker et al., 2017) and resources (Bultz et al., 2011). The social work profession is well positioned and skilled to take a leadership role in driving change (Loscalzo et al., 2015) to facilitate the integration of parenting supportive care into routine hospital palliative cancer care practice as they currently play an essential role in hospital palliative and cancer care teams and broader supportive care networks; compassionate patient- and family-centred care are part of core social work practice values and principles.

Future research

Due to the relative lack of research and evaluation of hospital-based parenting-related supportive care service responses to families experiencing terminal parental cancer who are raising at least one child up to 18 years old, any research initiatives focused on parenting supportive care practice that is integrated into routine hospital healthcare would be beneficial, particularly research examining practice from multi-stakeholder perspectives such as patients, co-parents and children. At a broad level, population-based and epidemiological studies are needed in Australia to better understand who these patients are, including the prevalence of patients parenting young children during palliative-stage cancer to assist with appropriately targeting parenting supportive care interventions.

Building on the thesis findings, a multi-site multi-regional study with a larger randomly-selected sample of patients and their families investigating the relationship between patients' clinical, sociodemographic, psychosocial factors and parenting support needs and the provision of parenting supportive care service could identify and quantify specific factors to include in parenting needs screening and assessment tools. Longitudinal studies investigating families' parenting supportive care needs from the point of IESC diagnosis to bereavement, identifying which needs are not routinely met through community-based formal services and informal supports, would provide further insight into which types of parenting support services should be offered by hospitals. Undertaking prospective studies that track parenting supportive care service access by patients along the IESC journey from parenting status screening at the start of palliative treatment to end of life services could possibly provide insights into trends associated with access or lack thereof.

A multi-site study investigating interdisciplinary hospital health professional parenting supportive care practices involving participants with various levels of practice experience could also assist with further identifying specific education, training, supervision and self-care needs for practitioners working with this patient and family subgroup. Evaluation studies exploring if education and skills learned are sustained in

practice and promote practitioners' facilitation of routine family-focused parenting supportive care would also be helpful. Other studies focusing on how education, training and supervision impacts on multidisciplinary practitioners' perceptions of organisation-based barriers such as time and resources, commonly cited across cancer care psychosocial intervention literature as factors impacting on service delivery and practitioner burnout, could also be of benefit.

Further, it is proposed that a clinical trial be conducted to evaluate the outcomes of implementing a systemised interdisciplinary parenting status screening and needs assessment procedure as part of routine hospital healthcare for patients from the time of IESC diagnosis—examining for instance, how many patients and families who are screened proceed to accessing parenting supportive care. Other outcomes to examine could include patient and co-parent perspectives on what was helpful, moving beyond self-reported satisfaction surveys and experiences to include psychosocial outcomes, and how access and delivery of interdisciplinary interventions could be enhanced. Obtaining multidisciplinary health professionals' perspectives on their views of delivery issues and ideas for process improvements, and identification of resource and service gaps.

It is recommended that future research should include wider input from multidisciplinary health professionals and families who have experienced palliative-stage parental cancer and also in the design, delivery and evaluation of practice recommendations presented in this thesis.

Conclusion

This study examined the hospital-based interdisciplinary supportive care response to patients' and co-parents' parenting-related concerns who are raising at least one child aged up to 18 years old and receiving palliative-stage cancer care. The thesis contributes to our understanding of the broad sociodemographic diversity of patients who may be raising young families and require supportive assistance with parenting; the challenging endeavour following IESC diagnosis that combines core parenting issues with a uniquely difficult set of psychosocial stressors. Insights into parents' and families'

strengths and resilience; interdisciplinary supportive care service responses delivered as an integrated component of routine hospital noncurative cancer care; and, what comprises evidence-informed optimal parenting supportive care from the perspectives of patients, co-parents and interdisciplinary health professionals—including factors these key stakeholders consider influence quality care responses. This thesis has argued that it is very important to consider patients' parent identity at this crucial period of life as part of quality routine holistic healthcare practice.

This study has uniquely captured patients' and co-parents' own considerations of parenthood during the palliative phase and their perspectives on hospital-based parenting service access and provision, including unmet needs and care preferences. These reflect the evolving parenting landscape and the value they place on health professional support and guidance. Interdisciplinary health professional perspectives shed light on the integral, shared and varied roles that individual professional disciplines play in parenting support delivery and the rationale for strengthening organisational structures and practitioner knowledge and skills that help facilitate patient-centred, family-focused supportive care. It is the first Australian study to explore hospital-based parenting-related supportive care offered as part of routine interdisciplinary supportive care. Longitudinal clinical data has confirmed how parenting issues may fluctuate over the IESC phase extending understandings of the importance of offering flexible and tailored parenting supportive care that is responsive to the individual needs of families.

The adoption of a patient-centred, family-focused approach to interdisciplinary parenting supportive care that is responsive, culturally-sensitive and trauma-informed may provide patients and their families with sufficient support and guidance to help ameliorate their psychosocial wellbeing by reducing parenting-related distress. Incorporating patient-centred, family-focused principles into clinical policy, guidelines and pathways together with targeted practitioner training and support could facilitate a systematic approach to interdisciplinary parenting-related supportive care. Creating a hospital environment and culture that promotes a safe, therapeutic and family-friendly space is also crucial in promoting wellbeing and family connection.

It is hoped the insights gained from this study will be used by researchers, policy-makers and health professionals to improve hospital-based interdisciplinary parenting support delivered to parents and their families who are experiencing IESC and to those who will experience it in the future.

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APPENDICES

APPENDIX 1

Phase I Study—Clinical Data Mining Audit Tool

Project No: 1

CLINICAL DATA MINING AUDIT TOOL

Patient Clinical, Socio-Demographic & Psychosocial Service Utilisation Data

☐ *Western Health Victoria Electronic Databases - iPM, BOSSNET & HMS*

☐ *Peter MacCallum Cancer Centre Victoria Electronic Databases – iPM, Verdi & Mosaiq*

Gender: ☐ Male ☐ Female

Date of Birth (DOB): _____

☐ **Patient deceased at time of audit**

☐ **Distress Screening completed** (MM/YYYY): _____

CLINICAL DATA

First / Primary diagnosis date (MM/YYYY): _____

Select One	Primary Cancer – Type
	Brain and spine
	Breast
	GIT (lower)
	GIT (upper)
	Gynaecological
	Haematological
	Head & Neck
	Lung
	Neurological
	Sarcoma
	Skin & Melanoma
	Urology
	Primary unknown
	Other:

Diagnosis of incurable end-stage cancer (MM/YYYY): _____

Select All That Apply	Palliative Treatment Received *Since diagnosis of incurable end-stage cancer*
	Chemotherapy
	Radiation therapy
	Surgery
	None
	Other:

Hospital Visits for Treatment *Since diagnosis of incurable end-stage cancer*				
First Visit (Date)	**Last Visit (Date)**	*** Last Visit – Discharge Destination**	****Primary Reason for Each Hospital Visit**	**Total Number of Visits**

***Discharge Destination**	
1	*Home*
2	*Family – not home*
3	*Hospice*
4	*Transfer to another hospital*
5	*Died in hospital*
6	*Other:*

****Primary Reason for Hospital Visits*** *Since diagnosis of incurable end-stage cancer*	
1	*Cancer diagnosis*
2	*Cancer treatment*
3	*End-of-life care*
4	*Social admission*
5	*Uncontrolled physical symptoms (pain, fatigue, other)*
6	*Other:*

Additional comments relevant to hospital admissions characteristics documented in patient medical records:

_____

_____

SOCIO-DEMOGRAPHIC DATA

Country of birth: _____

☐ **Identifies as Aboriginal or Torres Strait Islander (ATSI) Origin**

Primary language: _____

Other languages: _____

Select One	Interpreter
	Not needed
	Needed but not provided
	Provided (Select All That Apply) ☐ Professional Interpreter ☐ Hospital staff ☐ Family/friends ☐ Spiritual/religious ☐ Other
	Unknown (unclear)

Religion: _____

Select One	Place of Usual Residence
	Eastern Metro
	North Metro
	Southern Metro
	West Metro
	Barwon South-West
	Gippsland
	Grampians
	Hume
	Loddon-Mallee
	Interstate Details:
	International Details:

Select One	Parent Relationship Status *At time of diagnosis: incurable end-stage cancer*	Details
	Divorced	
	Married / de facto	
	Separated	
	Single	
	Widowed	
	Not stated	

Change in relationship status since diagnosis of incurable end-stage cancer?

☐ Yes ☐ No ☐ Not stated

Select One	Parental Relationship Type *At time of diagnosis: incurable end-stage cancer*
	Opposite-sex
	Same-sex
	Other:
	Not stated

Select One	Family Structure *At time of diagnosis: incurable end-stage cancer*
	Intact couple with children
	Blended family
	Single parent with children
	Kinship
	Other:
	Not stated

Change in family structure since diagnosis of incurable end-stage cancer?

☐ Yes ☐ No ☐ Not stated

Child Status *At time of diagnosis: incurable end-stage cancer*			
Child	**Age**	**Child**	**Age**
1		5	
2		6	
3		7	
4		8	
Additional children / ages:			

Select One	**Child Status First Documented by**
	Aboriginal Liaison Service
	Dietetics
	Doctor
	Nurse
	Occupational Therapy
	Palliative Care Team
	Pain Team
	Physiotherapy
	Psychiatry
	Psychology
	Speech Pathology
	Social Work
	Other:

Select All That Apply	**Identified Primary Carer of Patient** *At time of diagnosis: incurable end-stage cancer*
	Patient's partner / spouse
	Adult child [19 years +]
	Dependent child [0-18 years]
	Patient's Parent
	Patient's Sibling
	Other relative
	Friend
	Self
	Other:
	Not stated

Select All That Apply	**Identified Primary Carer/s of Children [0-18 years]** *At time of diagnosis: incurable end-stage cancer*
	Patient
	Patient's partner
	Grandparent
	Adult sibling
	Other relative
	Friend
	Other:
	Not stated

Select One	**Living Status** *At time of diagnosis: incurable end-stage cancer*
	Lives alone (no carer)
	Lives alone (day carer)
	Lives with spouse / partner
	Lives with spouse / partner and children
	Lives with children
	Lives with other relatives (not children)
	Lives with other relatives (with children)
	Residential facility
	Homeless / transient
	Other
	Not stated

Select One	**Employment Status** *At time of diagnosis: incurable end-stage cancer*	**Occupation Type** (*if known*)
	Employed full time	
	Employed part time	
	Casual	
	Self-employed / small business owner	
	Retired	
	Unemployed	
	Other:	
	Not stated	

Select All That Apply	**Income Status** *At time of diagnosis: incurable end-stage cancer*	
	Wage	
	Centrelink payment	Type:
	Income protection / insurance	
	Superannuation	
	TPD	
	Self-funded	
	Low income healthcare card	
	No income	
	Other:	
	Not stated	

Change of income status since diagnosis of incurable end-stage cancer?

☐ Yes ☐ No ☐ Not stated

Select One	**Highest Education Level**
	High school – Year 10
	High school – Year 12
	Certificate / Diploma
	University – undergraduate
	University – postgraduate
	Other:
	Not stated

PSYCHOSOCIAL SERVICE UTILISATION

Select All That Apply	Referral Source – Sunshine Hospital-based Psychosocial Services
	Patient
	Carer / family member
	Friend
	Doctor – Oncologist
	Doctor – Palliative Care Specialist
	Doctor – Other
	Nurse – Cancer Nurse Specialist
	Nurse – Ward based
	Social Worker
	Other Health Professional (Internal)
	External Social Worker
	External Health Professional
	Other:
	Not stated

Select All That Apply	Psychosocial Needs Identified	Health Professional (*Select from Health Professional List below - multiples allowed*)
	Accommodation – (treatment needs)	
	Adjustment to diagnosis or change in treatment plans	
	Bereavement, loss & grief – patient	
	Bereavement, loss & grief – partner	
	Bereavement, loss & grief – children [0-8] years	
	Bereavement, loss & grief – adult children [19+] years	
	Carer / family support – general	
	Child at risk	

	Cognitive competency / capacity	
	Community Service Coordination	
	Cultural/language issues	
	Domestic / family violence – other	
	Domestic / family violence – partner	
	Employment issues	
	Family conflict	
	Financial issues	
	Healthcare planning – patient	
	Housing / homelessness issues	
	Information – community resources & supports	
	Information – health care system	
	Legal (Advanced Care Directives, Power of Attorney, Family Law, Visas, Will)	
	Mental health – current	
	Mental health – past	
	Parenting – child behavioural / emotional / psychological issues	
	Parenting – child care	
	Parenting – coordinating children's hospital visits	
	Parenting – future planning (care plan, legal)	
	Parenting – memory making	
	Parenting – talking to children about cancer	
	Parenting – talking to children about death	
	Parenting – other:	
	Relationship issues – parental	
	Sexual health	
	Social support (limited supports, social isolation)	
	Spiritual / religious issues	

	Substance misuse – alcohol, drugs	
	Transport	
	Trauma History – Adverse child events (ACE) Recorded ☐ Emotional abuse ☐ Physical abuse ☐ Sexual abuse ☐ Mother treated violently ☐ Household substance abuse ☐ Mental illness in household ☐ Parental separation or divorce ☐ Criminal household member ☐ Emotional neglect ☐ Physical neglect	
	Trauma history – Other:	
	Travel	
	Work	
	Other:	
	Assessed but no psychosocial needs identified	
	Not stated	

Additional comments relevant to psychosocial needs documented in patient medical records:

Select All That Apply	Psychosocial Care Intervention/s Provided	Health Professional (HP) (*Select from HP List below- multiples allowed*)
	Care planning – end-of-life	
	Care planning – general	
	Carer support	
	Child protection interventions	
	Child – referral to external psychological services	
	Cognitive assessment / therapy	
	Community support service – referral & coordination	
	Counselling – carer	
	Counselling - children	
	Counselling – couple	
	Counselling – family (adults & children)	
	Counselling – patient	
	Drug & Alcohol – counselling / service referral	
	Family meeting – care planning / coordination &/or discharge planning	
	Fertility counselling	
	Financial assistance	
	Functional assessments / therapy	
	Genetic counselling	
	Information – community resources &/or supports	
	Internet access	
	Legal assistance	
	Parental guidance – child behavioural / emotional / psychological issues	
	Parental guidance & support – child care	
	Parental guidance & support – children's hospital visits	
	Parental guidance & support – future planning	
	Parental guidance & support – memory making	

	Parental guidance & support – referral to child psychological services	
	Parental guidance – talking to children about cancer	
	Parental guidance – talking to children about death	
	Pastoral / spiritual care referral	
	Professional-led support group	
	Psychosocial assessment	
	Rehabilitation / physical therapy	
	Sexual health counselling	
	Transport assistance	
	Other:	

Health Professional List
Aboriginal Liaison Service
Dietetics
Doctor
Nurse
Occupational Therapy
Palliative Care Team
Pain Team
Physiotherapy
Psychiatry
Psychology
Social Work
Speech Pathology
Other:

Additional comments relevant to psychosocial interventions documented in patient medical records:

_____

_____

☐ **Psychosocial service offered but declined by patient / family**

Comments: _____

_____

_____

_____

Select All That Apply	External Psychosocial Supports Identified *Since time of diagnosis: incurable end-stage cancer*	Details
	Family	
	Friends	
	Cancer Support Service (face-to-face)	
	Cancer Support Service (online)	
	Community service/s (face-to-face)	
	Community service/s (online)	
	Cultural community group	
	Home-based palliative care	
	Parenting Support Service (face-to-face)	
	Parenting Support Service (online)	
	Psychologist	
	Psychiatrist	
	Religious/Spiritual	
	Social Work	
	Other:	
	Not stated	

Additional comments relevant to external psychosocial supports documented in patient medical records:

_____

_____

_____

_____

APPENDIX 2

Phase II Study—Participant Invitation: Focus Group

PII Study Participant Invitation: Focus Group

We would like to invite your service to participate in a single health professional focus group as part of the study 'Patient-centred psychosocial care for parents with incurable end-stage cancer: Phase II' (HREC/17/WH/59). This study is part of a three-phased research project '*Patient-centred psychosocial care for parents with incurable end-stage cancer: an exploratory mixed methods study'* currently being conducted at the Western Health Sunshine Hospital as part of a PhD (The University of Melbourne).

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The purpose of this focus group study is to explore multidisciplinary health professionals' experience of providing hospital-based psychosocial supportive care to adult patients diagnosed with incurable end-stage cancer who are parenting one or more children aged from birth to 18 years old. Research evidence indicates that this patient group are at high risk of psychosocial distress, with parenting issues being a primary concern to them. Psychosocial supportive care provision is recognised as an integral element of cancer and palliative care, yet local and international evidence indicates that parents with incurable end-stage cancer do not routinely have their psychosocial needs addressed in the healthcare setting.

Recruitment criteria
Please select a staff member who has clinical experience working with at least two adult patients diagnosed with incurable end-stage cancer who were parenting one or more children aged from birth to 18 years old in the past two years (and received treatment at Sunshine Hospital).

Focus group details
Date: Wednesday 2 August 2017
Time: 12:15 – 13: 25
Location: Sunshine Hospital 'Wellbeing Program Room' (previous 'Old Day Hospice Room / current inpatient palliative care team MDT meeting room) located near the Palliative Care Unit
Number of participants: 8-12
Catering: Lunch will be served at 12:15 *please advise Vera Steiner of any special dietary requirements by COB Wednesday 26 July 2017
Participant Information and Consent (PICF) form: The form will be explained and a copy provided on the day. All participants will need to sign the form prior to partaking in the session (refer copy attached)
Participant Demographic Information form: The form will be explained and provided on the day (refer copy attached)

RSVP: Please confirm who the nominated participant will be by Thursday 27 July 2017 (Vera Steiner vsteiner@student.unimelb.edu.au)
All enquiries: Vera Steiner vsteiner@student.unimelb.edu.au

APPENDIX 3

Phase II Study—Participant Demographic Information Sheet

Phase II Study: Participant Demographic Information

Date: ___/___/___

Please tick the relevant box:

1) **Gender**: ☐ Male ☐ Female

2) **Profession**:

Medical

☐ Oncology ☐ Palliative Care ☐ Other: _____

Nursing

☐ Oncology ☐ Palliative Care ☐ Other: _____

Allied Health

☐ Clinical Psychology ☐ Occupational Therapy ☐ Pastoral Care Service

☐ Physiotherapy ☐ Social Work – Oncology ☐ Social Work – Palliative Care

Aboriginal Health Unit

☐ Aboriginal health worker

3) **Years of Professional Experience:** _____

APPENDIX 4

Phase II Study—Participant Information and Consent Form

Participant Information and Consent Form

Version: 1 **Dated:** 25/4/2017
Site: Western Health Sunshine Hospital, Victoria

Full Project Title: Patient-centred psychosocial care for parents with incurable end-stage cancer: Phase II

Principal Investigator
Dr Anita Morris
M: 0438 159282
E: Anita.Morris@wh.org.au

Associate Investigator
Vera Steiner
M: 0413 754416
E: vsteiner@student.unimelb.edu.au

This Participant Information and Consent Form is 7 pages long. Please make sure you have all the pages.

1. Your Consent
You are invited to take part in this research project.

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it. Please read this Participant Information carefully. Feel free to ask questions about any information in the document.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project. You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background
The purpose of this project is to explore multidisciplinary health professionals' experience of providing hospital-based psychosocial supportive care to adult patients diagnosed with

incurable end-stage cancer and parenting one or more children aged from birth to 18 years old. A total of 8 – 12 health professionals will participate in this project.

Parents with incurable end-stage cancer who are parenting one or more children aged from birth to 18 years old face unique psychosocial supportive care needs. Research evidence indicates that this patient group are at high risk of psychosocial distress, with parenting issues being a primary concern to them. Psychosocial supportive care provision is recognised as an integral element of cancer and palliative care, yet local and international evidence indicates that parents with incurable end-stage cancer do not routinely have their psychosocial needs addressed in the healthcare setting.

You are invited to participate in this research project because you have been identified as a health professional that has experience in the past two years of working with patients who are parents with incurable end-stage cancer that are parenting one or more children aged from birth to 18 years old.

This study is Phase II of a three-phased exploratory mixed method research project being undertaken by the Associate Researcher Vera Steiner as part of a Doctor of Philosophy (PhD) at The University of Melbourne and supported by an Australian Government Research Training Program Scholarship.

3. Procedures

Participation in this project will involve a one-hour focus group that will be held at the Western Health Sunshine Hospital, Victoria. The focus group will comprise 8 – 12 Western Health multidisciplinary health professionals from the medical, nursing and allied health disciplines and Aboriginal Health Unit. The session will be facilitated by the Associate Researcher Vera Steiner and digitally audio-recorded.

4. Possible Benefits

Possible benefits include the collaborative sharing of expert knowledge and professional experience. At a broader level, data collected from this study will contribute to developing an understanding of health professionals' experiences of providing parenting-focused psychosocial supportive care to this patient group and what facilitates or hinders of its delivery in the hospital setting. We cannot guarantee or promise that you will receive any benefits from this project.

5. Possible Risks

It is anticipated that there will be no potential risks, side effects and/or discomfort to participants. Participation is completely voluntary. You are able to withdraw from the study at any stage if distress occurs. If any unforeseen or unknown risks arise, free counselling support can be accessed by all Western Health employees via the Employee Assistance Program (EAP).

6. Alternatives to Participation

You do not have to participate in this research project. Participation is completely voluntary.

If you are interested in participating in the focus group but are unable to attend on the day, an individual interview in lieu of the session can be organised with the Associate Researcher. The individual interview will be conducted at a mutually convenient time within two weeks of the scheduled date of the focus group. Participants will have the option to the complete the individual interview via phone, Skype or in-person at Western Health Sunshine Hospital, Victoria. The interview will be digitally audio-recorded.

7. Privacy, Confidentiality and Disclosure of Information

Any information obtained in connection with this project that can identify you will remain confidential. It will only be disclosed with your permission, except as required by law. As a participant, you are requested to respect the confidentiality of all others involved in the focus group and not share information outside of the group.

All data will be kept strictly confidential according to the NHMRC National Statement on Ethical Conduct in Human Research 2007 (and updates) and the Australian Code for Responsible Conduct of Research 2007. Data will be stored in unidentifiable format in a password protected folder on the Western Health shared drive. Research data will only be accessible by research team members. Data collected will only be used for this research project.

Research data will be stored on the Western Health shared drive for a period of at least five years. After five years these files will be destroyed by erasure unless further approval for retention is obtained. The Western Health Principal Investigator will be responsible for the security of the data and its destruction.

If you give us your permission by signing the Consent Form, the study results will be published as part of the PhD thesis, submitted for publication in scholarly journals, and presented at professional conferences. In any publication, information will be provided in such a way that you cannot be identified. Excerpts from the discussions in both studies will be selected for inclusion in the results. Identities will be protected by the removal of any identifying information.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws you have the right to access the information collected and stored by the researchers about you. You also have the right to request that any information with which you disagree be corrected. Please contact one of the researchers named below if you would like to access your information.

8. New Information Arising During the Project

During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation. In all cases, you will be offered all available care to suit your needs.

9. Results of Project
Participants can find out about the study results when the research project is completed. Study results will be published as part of the PhD thesis, submitted for publication in scholarly journals, and presented at professional conferences.

11. Further Information or Any Problems
If you require further information or if you have any problems concerning this project, you can contact Vera Steiner, Associate researcher. The researchers responsible for this project are Dr Anita Morris, Principal Researcher (Mobile: 0438 159282) and Vera Steiner, Associate Researcher (M: 0413 754416).

12. Other Issues
If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

Position:	Manager, Western Health Office for Research
Telephone:	(03) 8395 8073
Email:	ethics@wh.org.au

(You will need to tell the Manager the name of one of the researchers given in section 11 above.)

13. Participation is Voluntary
Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with Western Health.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw. This notice will allow that person or the research supervisor to inform you if there are any health risks or special requirements linked to withdrawing.

14. Ethical Guidelines
This project will be carried out according to the *National Statement on Ethical Conduct in Human Research* (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Western Health Low Risk Human Research Ethics Panel. The research study has been approved to be conducted at the Western Health Sunshine Hospital, Victoria.

15. Reimbursement for your costs

You will not be paid for your participation in this project.

Western Health

THE UNIVERSITY OF MELBOURNE

CONSENT FORM

Version: 1 **Dated:** 25/4/2017
Site: Western Health Sunshine Hospital, Victoria
Project title: Patient-centred psychosocial care for parents with incurable end-stage cancer: Phase II

I have read and I understand the Participant Information version 1 dated 25/4/2017.

I freely agree to participate in this project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant's Name: _____

Participant's Signature: _____**Date**: ___/___/___

Witness's Name: _____

Witness's Signature: _____**Date**: ___/___/___

Researcher's Name: _____

Witness's Signature: _____**Date**: ___/___/___

Declaration by researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

** A senior member of the research team must provide the explanation and provision of information concerning the research project.*
Note: All parties signing the Consent Form must date their own signature.

REVOCATION OF CONSENT FORM

Full Project Title: Patient-centred psychosocial care for parents with incurable end-stage cancer: Phase II

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with Western Health.

Participant's Name: _____

Participant's Signature: _____**Date**: ___/___/___

APPENDIX 5

Phase III Study—Participant Clinical and Demographic Information Form

---

Phase III Study: Participant Clinical & Demographic Information

Date: ___/___/___

***Please tick the relevant boxes*:**

☐ Patient ☐ Co-Parent **Gender** ☐ Male ☐ Female

Year of Birth: _____ **Postcode of usual residential address**: _____

Country of Birth: _____

Primary Language/s: _____ **Interpreter required**: Y / N

Patients only:

Cancer type	
Date of Cancer Diagnosis	*(when curative treatment no longer the focus of treatment)*
Co-parent is your:	☐ Partner ☐ Ex-partner ☐ Not applicable ☐ Relative (*details*): _____ ☐ Other: _____
Age & gender of children	**Child 1**: ___ ☐Male ☐Female **Child 2**: _____ ☐Male ☐Female **Child 3**: ___ ☐Male ☐Female **Child 4**: _____ ☐Male ☐Female **Child 5**: ___ ☐Male ☐Female **Child 6**: _____ ☐Male ☐Female **Child 7**: ___ ☐Male ☐Female **Child 8**: _____ ☐Male ☐Female
Relationship status	☐ Single ☐ Partnered/married ☐ Separated/divorced ☐ Other (*details*): _____
Living Arrangements	☐ Alone ☐ Children only (ages:_____) ☐ Partner/spouse only ☐ Partner & children (ages: _____) ☐ Other(*details*): _____
Income source	☐ Centrelink benefit: _____ ☐ Wage ☐ No income ☐ Other: _____

APPENDIX 6

Phase III Study—Participant Information and Consent Form

Western Health

THE UNIVERSITY OF MELBOURNE

Booklet

WHCOR26

Western Health Low Risk Human Research Ethics Panel

Participant Information and Consent Form

Version: 1 **Dated**: 25/4/2017
Site: Western Health Sunshine Hospital, Victoria

Full Project Title: Patient-centred psychosocial care for parents with incurable end-stage cancer: Phase III

Principal Investigator
Dr Anita Morris
M: 0438 159282
E: Anita.Morris@wh.org.au

Associate Investigator
Vera Steiner
M: 0413 754416
E: vsteiner@student.unimelb.edu.au

This Participant Information and Consent Form is 7 pages long. Please make sure you have all the pages.

1. Your Consent
You are invited to take part in this research project.

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it. Please read this Participant Information carefully. Feel free to ask questions about any information in the document.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project. You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background
Parents with end-stage cancer who are caring for one or more children aged from birth to 18 years old can sometimes need support. Research has shown that one of the main concerns for parents with end-stage cancer is how to manage caring for their children during this time. It can be a distressing time for parents and their families. Providing high quality support to parents in this situation is considered to be an important part of healthcare. Studies however have shown that parents do not routinely have their parenting support needs addressed in the hospital setting.

The aims of this research project are to explore:

1) How patients talk to the hospital healthcare team about their parenting support needs when they are caring for children aged 18 years and younger

2) What types of support parents have received and what has been most helpful

3) What support that would have been helpful, that were not received

A total of eight families will participate in this project.

You are invited to participate in this research project because you have been identified as a person who has end-stage cancer (or a 'co-parent' with someone who has end-stage cancer) and you are parenting one or more children aged 18 years old or younger..

This study is Phase II of a three-phased exploratory mixed method research project being undertaken by the Associate Researcher Vera Steiner as part of a Doctor of Philosophy (PhD) at The University of Melbourne and supported by an Australian Government Research Training Program Scholarship.

3. Procedures
Participation in this project will involve a 45-60 minute individual interview with the Associate Researcher. The interview will be held at the Western Health Sunshine Hospital, Victoria and digitally audio-recorded.

4. Possible Benefits
Possible benefits you may have from being involved in this study, include the opportunity to share your experience of being a parent and providing feedback about what support has been helpful, and how support provided in the hospital setting can be improved, which for some can be satisfying. You will have the knowledge that the information you have provided will contribute to improving support services for other parents with children. We cannot guarantee or promise that you will receive any benefits from this project.

5. Possible Risks
There is a possible minimal risk of emotional discomfort to participants. Participation in the study is completely voluntary. You are able to withdraw from the study at any stage. If feel upset during the interview and consent to speak to a counsellor, a referral will be made to

the Western Health social work service. This is a free service. As part of this study, all participants will receive a copy of the Counselling Services Information Sheet.

6. Alternatives to Participation
You do not have to participate in this research project. Participation is completely voluntary.

7. Privacy, Confidentiality and Disclosure of Information
Any information obtained in connection with this project that can identify you will remain confidential. It will only be disclosed with your permission, except as required by law.

All data will be kept strictly confidential according to the NHMRC National Statement on Ethical Conduct in Human Research 2007 (and updates) and the Australian Code for Responsible Conduct of Research 2007. Information will be stored in a password protected folder on the Western Health shared drive. Research data will only be accessible by research team members. Data collect will only be used for this research project.

Research data will be stored on the Western Health shared drive for a period of at least five years. After five years these files will be destroyed by erasure unless further approval for retention is obtained. The Western Health Principal Investigator will be responsible for the security of the data and its destruction.

If you give us your permission by signing the Consent Form, the study results will be published as part of the PhD thesis, submitted for publication in scholarly journals, and presented at professional conferences. In any publication, information will be provided in such a way that you cannot be identified.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws you have the right to access the information collected and stored by the researchers about you. You also have the right to request that any information with which you disagree be corrected. Please contact one of the researchers named below if you would like to access your information.

8. New Information Arising During the Project
During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation. In all cases, you will be offered all available care to suit your needs.

9. Results of Project
Participants can find out about the study results when the research project is completed. Study results will be published as part of the PhD thesis, submitted for publication in scholarly journals, and presented at professional conferences.

11. Further Information or Any Problems
If you require further information or if you have any problems concerning this project, you can contact Vera Steiner, Associate researcher. The researchers responsible for this project

are Dr Anita Morris, Principal Researcher (Mobile: 0438 159282) and Vera Steiner, Associate Researcher (M: 0413 754416).

12. Other Issues
If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

Position:	Manager, Western Health Office for Research
Telephone:	(03) 8395 8073
Email:	ethics@wh.org.au

(You will need to tell the Manager the name of one of the researchers given in section 11 above.)

13. Participation is Voluntary
Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with Western Health.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw. This notice will allow that person or the research supervisor to inform you if there are any health risks or special requirements linked to withdrawing.

14. Ethical Guidelines
This project will be carried out according to the *National Statement on Ethical Conduct in Human Research* (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.
The ethical aspects of this research project have been approved by the Western Health Low Risk Human Research Ethics Panel. The research study has been approved to be conducted at the Western Health Sunshine Hospital, Victoria.

15. Reimbursement for your costs
You will not be paid for your participation in this project. However you will be offered $20 reimbursement for out-of-pocket expenses for parking costs.

CONSENT FORM

Version: 1 **Dated**: 25/4/2017 **Site:** Western Health Sunshine Hospital, Victoria **Project title:** Patient-centred psychosocial care for parents with incurable end-stage cancer: Phase III

I have read and I understand the Participant Information version 1 dated 25/4/2017.

I freely agree to participate in this project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant's Name: _____

Participant's Signature: _____**Date**: ___/___/___

☐ **Verbal consent provided** **Date**: ___/___/____

Witness's Name: _____

Witness's Signature: _____**Date**: ___/___/___

Researcher's Name: _____

Witness's Signature: _____**Date**: ___/___/___

Declaration by researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.
* *A senior member of the research team must provide the explanation and provision of information concerning the research project.*
Note: All parties signing the Consent Form must date their own signature.

REVOCATION OF CONSENT FORM

Full Project Title: Patient-centred psychosocial care for parents with incurable end-stage cancer: Phase III

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with Western Health.

Participant's Name: _____

Participant's Signature: _____ **Date**: ___/___/_____

OR

☐ **Verbal consent provided** **Date**: ___/___/_____

APPENDIX 7

Phase III Study—Support Services Information Sheet

Western Health

THE UNIVERSITY OF MELBOURNE

Phase III Study

Support Services Information Sheet

The following Support Services are a guide to some of the services available.

Aboriginal Health Unit - Western Health Sunshine Hospital

The Aboriginal Health Unit is passionate and committed to providing the Aboriginal and Torres Strait Islander Community a safe and welcoming environment at all of our services. As an Aboriginal and Torres Strait Islander using our service we will provide you and your family:

- emotional, social and cultural support
- a connection between you and non-Indigenous staff
- assistance through the hospital system, including relevant referrals to other agencies

Phone: (03) 8345 1333

Australian Centre for Grief and Bereavement

This service provides information and support to people caring for children and adolescents who have been affected by trauma and loss.

Phone: (03) 9625 2100

Cancer Council Victoria

The Cancer Council offers a range of information and services to help people with cancer, their families and friends.

Phone: 13 11 20

General Practitioner (GP)

A good starting point is to talk to your local doctor about how you are feeling. If needed, they can refer you to other health professionals for further support.

Griefline

Counselling support services for individuals and families.

Open: 12 noon to 3.00 am

Phone: (03) 9935 7400

Kids Helpline

Kids Helpline is a telephone, web and email counselling service with an interactive website for children, adolescents and young adults. It offers confidential counselling for issue worrying a child.

Phone: 1800 55 1800

Lifeline

A general telephone counselling service that is free.

Phone: 13 11 14

Mercy Grief Services

A free bereavement counselling service for anyone experiencing bereavement.

Phone: (03) 9313 5700

Social Work Service - Western Health Sunshine Hospital

Western Health Social Workers provide information, support and counselling to patients and their family/carer as they adjust to hospital, cope with changed health needs and determine the most appropriate care to meet their needs.

Open: Monday to Friday 8:00 am – 4.30 pm

Phone: (03) 8345 6666

Victorian Aboriginal Health Service

VAHS offers free counselling for families within the Aboriginal community.

Phone: (03) 9403 3300

APPENDIX 8

Training Topics—Interdisciplinary Health Professionals

Training Topics: Interdisciplinary Health Professionals

—Strengthening Parenting Supportive Care Practice—

Topic category	Topic examples
1. Overview: Adult patients diagnosed with IESC, parenting young children	1. Prevalence: Patients with IESC who are parenting young children aged 18 years and younger[4, 5, 6, 7, 8] 2. Parenting: A primary psychosocial stressor[9, 10, 11, 12, 13] 3. Nature and types of parenting-related concerns (E.g., Change over incurable end-stage cancer [IESC] treatment period)[14, 15, 16, 17] 4. Impact of parenthood on the patient experience[18, 19] (E.g., Medical treatment decision-making[20]) 5. Ad hoc delivery of parenting supportive care in the healthcare setting[21, 22, 23]

[4] World Health Organization (2015). *Cancer Fact Sheet No.297*. Retrieved from http://www.who.int/

[5] Bray, E. Ferlay, J. Soerjomataram, I. Siegel, R. Torre, L. & Jemal, A. (2018). Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: a cancer journal for clinicians*, *68*, 394–424. doi:10.3322/caac.21492

[6] National Cancer Institute (2019). *Survival*. Retrieved from https://www.progressreport.cancer.gov/after/survival

[7] Australian Institute of Health & Welfare (2019). *Cancer in Australia 2019*. Retrieved from https://www.aihw.gov.au/getmedia/8c9fcf52-0055-41a0-96d9-f81b0feb98cf/aihw-can-123.pdf.aspx?inline=true

[8] Phillips, F. & Lewis, F. (2015). The adolescent's experience when a parent has advanced cancer: A qualitative inquiry. *Palliative Medicine*, *29*, 851–858. doi:10.1177/0269216315578989

[9] Park, E. Deal, A. Check, D. Hanson, L. Reeder-Hayes, K. Mayer, D., . . . Rosenstein, D. (2016). Parenting concerns, quality of life, and psychological distress in patients with advanced cancer. *Psycho-Oncology*, *25*, 942–948. doi:10.1002/pon.3935

[10] Steiner, V. Joubert, L. Shlonsky, A. & Hocking, A. (2020). Australian hospital-based parenting support for adults with incurable end-stage cancer: Parent perspectives. *Journal of Evidence-Based Social Work, 17*(2), 172–190. doi:10.1080/26408066.2019.1705957

[11] Turner, J. Clavarino, A. Yates, P. Hargraves, M. Connors, V. & Hausmann, S. (2007). Development of a resource for parents with advanced cancer: What do parents want? *Palliative and Supportive Care*, *5*, 135–145. doi:10.1017/S1478951507070204

[12] Zaider, T. Salley, C. Terry, R. & Davidovits, M. (2015). Parenting challenges in the setting of terminal illness: A family-focused perspective. *Current opinion in supportive and palliative care*, *9*, 52–57. doi:10.1097/SPC.0000000000000114

[13] Hailey, C. Yopp, J. Deal, A. Mayer, D. Hanson, L. Grunfeld, G. & Rosenstein, D. (2018). Communication with children about a parent's advanced cancer and measures of parental anxiety and depression: A cross-sectional mixed-methods study. *Supportive Care in Cancer, 26*, 287–295. doi:10.1007/s00520-017-3847-9

[14] Steiner, V. Joubert, L. Shlonsky, A. & Dabscheck, A. (n.p.). Parenting in the palliative stage: A clinical data-mining study of hospital-based supportive care. Submitted for publication.

[15] Steiner, V. Joubert, L. Shlonsky, A. & Hocking, A. (2020). Australian hospital-based parenting support for adults with incurable end-stage cancer: Parent perspectives. *Journal of Evidence-Based Social Work, 17*(2), 172–190. doi:10.1080/26408066.2019.1705957

[16] Zaider, T. Salley, C. Terry, R. & Davidovits, M. (2015). Parenting challenges in the setting of terminal illness: A family-focused perspective. *Current opinion in supportive and palliative care*, *9*, 52–57. doi:10.1097/SPC.0000000000000114

[17] Turner, J. Clavarino, A. Yates, P. Hargraves, M. Connors, V. & Hausmann, S. (2007). Development of a resource for parents with advanced cancer: What do parents want? *Palliative and Supportive Care*, *5*, 135–145. doi:10.1017/S1478951507070204

[18] Steiner, V. Joubert, L. Shlonsky, A. & Hocking, A. (2020). Australian hospital-based parenting support for adults with incurable end-stage cancer: Parent perspectives. *Journal of Evidence-Based Social Work, 17*(2), 172–190. doi:10.1080/26408066.2019.1705957

[19] Check, D. Park, E. Reeder-Hayes, K. Mayer, D. Deal, A. Yopp, J., . . . Hanson, L. (2017). Concerns underlying treatment preferences of advanced cancer patients with children. *Psycho-Oncology*, *26*, 1491–1497. doi:10.1002/pon.4164

[20] Nilsson, M. Maciejewski, P. Zhang, B. Wright, A. Trice, E. Muriel, A., . . . Prigerson, H. (2009). Mental health, treatment preferences, advance care planning, location, and quality of death in advanced cancer patients with dependent children. *Cancer*, *115*, 399–409. doi:10.1002/cncr.24002

[21] Turner, J. Clavarino, A. Yates, P. Hargraves, M. Connors, V. & Hausmann, S. (2007). Development of a resource for parents with advanced cancer: What do parents want? *Palliative and Supportive Care*, *5*, 135–145.

[22] Steiner, V. Joubert, L. Shlonsky, A. & Hocking, A. (2020). Australian hospital-based parenting support for adults with incurable end-stage cancer: Parent perspectives. *Journal of Evidence-Based Social Work, 17*(2), 172–190. doi:10.1080/26408066.2019.1705957

[23] Inhestern, L. Haller, A. Wlodarczyk, O. & Bergelt, C. (2016). Psychosocial interventions for families with parental cancer and barriers and facilitators to implementation and use: A systematic review. *PLOS ONE*, *6*, 1–20. doi:10.1371/journal.pone.0156967

Topic category	Topic examples
2. Understanding the psychosocial context: parenting with IESC	1. Psychosocial context of parenthood: IESC stage[24, 25, 26] 2. Impact on patients with IESC (E.g., Adjustment; anticipatory grief & loss; death anxiety; traumatic growth)[27, 28, 29] 3. Impact on co-parents[30, 31, 32] 4. Impact on children[33, 34, 35] 5. Parenting challenges of different families (E.g., single-parenting)[36, 37] 6. Family functioning (E.g., Parent-child & parent-parent communication, families at risk)[38, 39, 40] 7. Parental death[41, 42, 43]

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Topic category	Topic examples
3. Hospital-based interdisciplinary response to patients' parenting concerns	1. Practice approach (Interdisciplinary, integrated into routine care, family-focused, tailored, trauma-informed, culturally & spiritually sensitive)[44, 45, 46, 47, 48] 2. Practice theoretical frameworks (E.g., Family systems, Life course theory)[49, 50] 3. Family-friendly hospital environments[51] 4. What patients, co-parents & children want from health professionals[52, 53, 54] 5. Clinical pathway (Referrals, screening, assessment, interventions & continuity of care)[55] 6. Strategies for engaging with patients and their families (E.g., Initiating parenting-related conversations)[56, 57] 7. Collaborative interdisciplinary team practice & scope of practice[58, 59] 8. Transitioning from curative to noncurative treatment (Discussing diagnosis & prognosis news with parents & families)[60, 61, 62, 63]

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Topic category	Topic examples
	9. Patients' & families' strengths, resiliency & traumatic growth[64, 65] 10. Utilising existing practice strategies & tools (E.g., Parenting Concerns Questionnaire[66]); assessing individual/family strengths & support networks (E.g., Genogram[67])
4. Assisting families to navigate the IESC journey	1. Cancer treatment choices (E.g., Prolonging life vs living as normal as possible; transitioning to palliative care goals; impact of treatment on family)[68, 69] 2. End-of-life communication: Helping parents talk with their children about cancer & death (E.g., Why, when & how to share; clarifying children's understanding of cancer progression & parent's imminent death; clarifying parents' understanding of each other's parenting support needs & children's support needs)[70, 71, 72, 73, 74, 75, 76] 3. Parental communication (E.g., Dying parents' wishes, future parenting & legacy)[77, 78] 4. Health professionals: Planning to share news of cancer progression & treatment plans[79, 80]

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Topic category	Topic examples
	5. Current & future parenting concerns, children's adjustment (E.g., Individual child's coping responses: developmental stages & temperament; daily routines; quality family time; legacy leaving including memory-making, school & afterschool activities; organising & engaging with broader community supports; connecting with schools; funeral preparation; funeral attendance: a choice; changing roles; explaining that death occurred & why)[81, 82, 83, 84] 6. Choices about where to die (E.g., Hospital vs home; impact of choices on patient, co-parent & children; child-friendly, family-inclusive end-of-life & funeral practice)[85, 86, 87] 7. Last visits[88] (E.g., Confirming if children should visit in hospital: parents' viewpoints; preparing parents & children; options for engaging; final words; addressing distressing situations: children not wanting to visit/parent not wanting child to visit) 8. Children's grief: Emotions & developmental perspective[89, 90, 91, 92] 9. Bereavement care: Co-parents & children[93, 94, 95, 96] 10. Parenting practice resource toolkit (Including existing hospital, community & internet resources; general & specialised support options: patient, co-parent

[81] Ibid.
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Topic category	Topic examples
	& family-based) [*collated by hospitals taking into consideration specific needs of parental community e.g., cultural, language & spiritual needs*][97]
5. Strengthening practice: challenges & strategies	1. Factors influencing optimal practice barriers: organisation, health professional & parents/family[98, 99, 100, 101] 2. Parent-parent relationships & communication: (E.g., Sharing diagnosis, prognosis & treatment news with children; readiness to talk about their disease and parenting matters; divergent views on parenting)[102, 103, 104] 3. Family conflict & violence, divorce, separation & single parenting[105, 106, 107] 4. Current & historical trauma experiences[108] 5. Legal matters: including Guardianship, visas, child protection[109, 110] 6. Pre-existing psychiatric conditions in children[111] 7. When spiritual, cultural &/or religious beliefs conflict with professional perspectives of optimal parenting practice[112] 8. Communication strategies for challenging conversations[113]

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Topic category	Topic examples
6. Strengthening practice: health professional care	1. Emotional & psychological impact of palliative oncology parenting-focused practice on health professionals[114] 2. Formal & informal supervision: Models, individual & peer; benefits & limitations[115] 3. Palliative & oncology practice support groups & networks: in-hospital or community[116] 4. Self-care: Vicarious trauma (E.g., Cultivating Emotional Balance[117]; mindfulness-based training[118]) & resiliency[119]

[114] Turner, J. Clavarino, A.Yates, P. Hargraves, M. Connors, V. & Hausmann, S. (2007). Oncology nurses, perceptions of their supportive care for parents with advanced cancer: Challenges and educational needs. *Psycho-Oncology, 16*, 149–157. doi:10.1002/pon.1106

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APPENDIX 9

Dissemination

Publications / manuscripts

Conference and other presentations

Awards / Funding grants

Publications/manuscripts

2020 Steiner, V. Joubert, L. Shlonsky, A. & Hocking, A. (2020). Australian hospital-based parenting support for adults with incurable end-stage cancer: Parent perspectives. *Journal of Evidence-Based Social Work*, *17*(2), 172–190. doi:10.1080/26408066.2019.1705957

Steiner, V. Shlonsky, A. Joubert, L. & Morris, A. (n.p.). Hospital parenting support for adults with incurable end-stage cancer: multidisciplinary health professional perspectives. Manuscript accepted 30 July 2020 for publication in *Health and Social Work*.

Joubert, L. Collins, M. Braddy, L. Turner, K. Hocking, A. Beovich, D. Blaschke, S. Wiseman, F. & Steiner, V. (2020). Clinical data mining: A practice research methodology of choice for health social workers. Joubert, L. & Webber, M. (Eds.), *The Routledge Handbook of Social Work Practice Research* (pp. 93–104). NY, Routledge.

2019 Steiner, V. Joubert, L. Shlonsky, A. & Dabscheck. A. (n.p.). Parenting in the palliative stage: A clinical data-mining study of hospital-based supportive care. Manuscript submitted for publication.

2017 Steiner, V. Shlonsky, A. & Joubert, L. (2017). Psychosocial interventions for parents with incurable end-stage cancer: A rapid evidence assessment: *Australian Psychologist*, *52*, 381–391. doi:10.1111/ap.12286

Conference and other presentations

2019 **Western Health Social Work Department**. Exploring parenting-focused support for adult patients living with a poor prognosis. (Oral paper). Melbourne, VIC, Australia: November 27, 2019.

Oncology Social Work Australia & New Zealand (OSWANZ) Conference. Exploring parenting-focused support for adult patients living with a poor prognosis. (Oral paper). Hobart, TAS, Australia: November 22, 2019.

Katie Rose Cottage Hospice staff. Parenting supportive care for palliative parents. (General presentation). Sunshine Coast, QLD, Australia: January 21, 2019.

2018 **Oncology Social Work Australia (OSWA) National Conference.** Exploring the hospital-based parenting supportive care experiences of parents diagnosed with IESC who are parenting children (up to 18 years old): A qualitative study. (Oral paper). Canberra, Australian Capital Territory (ACT), Australia: November 8, 2018.

2017 **OSWA ACT Group, Canberra, Australia.** Addressing the psychosocial supportive care needs of parents with incurable end-stage cancer. (Oral paper). Canberra, Australia: November 7, 2017.

ACT Health Social Work Research Interest Group. Patient-centred psychosocial supportive care practices: Parents with incurable end-stage cancer. (Oral paper). Canberra, Australia: October 17, 2017.

Melbourne School of Health Sciences Research Higher Degree Colloquium. Addressing the psychosocial supportive care needs of parents with incurable end-stage cancer. (Oral paper). The Melbourne University, Melbourne, Australia: October 30, 2017.

4th International Conference on Practice Research. Patient-centred psychosocial supportive care practices: Parents with incurable end-stage cancer. (Oral paper). Hong Kong, People's Republic of China: May 24, 2017.

2nd Victorian Allied Health Research Conference. Psychosocial care needs of parents with incurable end-stage cancer. (Oral paper). Melbourne, Australia: March 31, 2017.

The University of Melbourne Department of Social Work Research Higher Degree Colloquium. Sliding doors: Parenting with incurable end-stage cancer. (Oral paper). The Melbourne University, Melbourne, Australia: March 15, 2017.

2016 **8th International Conference on Social Work in Health and Mental Health.** Parenting during palliation: Psychosocial supportive care interventions for parents with incurable advanced cancer who have dependent children. (Poster presentation). June 19–22, 2016.

OSWA National Conference. Parenting during palliation: psychosocial intervention programs for adults with incurable end-stage cancer who are parenting dependent children. (Oral paper). Melbourne, Australia: October 7, 2016.

Awards/Funding grants

2015–2019 Australian Government Research Training Program Scholarship

2019 OSWANZ Travel Conference Travel Grant

2015 Melbourne Abroad Travel Grant, The University of Melbourne, Melbourne, Australia