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THE EXPERIENCES OF PARENTS DIAGNOSED WITH CANCER WHILST PARENTING MINOR-AGED CHILDREN

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A thesis submitted for the Degree of Master of Philosophy

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Declaration

I declare that, to the best of my knowledge, this thesis contains no material previously published by another person, except where due acknowledgement has been made in the text of the thesis. I further declare that this is my own work and contains no material which has been accepted for the award of any degree or diploma in any academic institution.

George Prince
July 2023

Abstract

The incidence of cancer in Australia for people in the parenting age range is significant, and as the fertility rate of women aged 35 years and over continues to rise, many cancer patients may be parenting minor-aged children. The aim of this research was therefore to explore the lived experience of parents diagnosed with cancer whilst parenting minor-aged children, and to gain knowledge and understanding as to how parents and their families respond to a parent's cancer illness. Utilising a qualitative research design, eight participants, receiving treatment for cancer in a private hospital cancer treatment service, and parenting at least one child under the age of 18 years, were recruited for semi-structured interviews to gain an understanding of their experiences. The data was subjected to a thematic analysis and the findings of the study revealed three major themes: Hearing the words 'you have cancer', bringing cancer home to the family, and playing the hand you are dealt. For the parents in this study, the need to protect children motivated how they and their families communicated about the parent's illness, and what strategies they used to maintain a stable family environment. The findings of the study raise questions around the importance of emotional expression in families dealing with a parent's cancer diagnosis, and how this influences individual and family functioning, as well as the parent's capacity to cope with the demands of the illness. New ideas around the concept of family-focused medical care for parents with cancer, and the working relationship between parents with cancer and the health care professionals involved in their cancer treatment, are also discussed. Suggestions for future directions in research into these aspects of the study findings are offered.

Keywords: parental cancer, children, family coping, health professionals, qualitative

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1 Introduction

Cancer is a leading cause of illness in Australia and significantly affects the personal, social and economic wellbeing of individuals, families and communities (Australian Institute of Health and Welfare [AIHW], 2019). Advances in diagnostic screening, medical treatment and preventative education have seen cancer shift from an acute-type to a chronic-type illness, with many people living with cancer for prolonged periods (AIHW, 2019; Boerger-Knowles & Ridley, 2014; Golby, 2014). Nevertheless, despite these advances, cancer accounts for 3 out of every 10 deaths in Australia (AIHW, 2019) and it is estimated 50,000 people will die in Australia from cancer in 2022 (AIHW, 2022). A cancer diagnosis represents a highly salient threat to an individual's life, entails intense and potentially expensive treatments with no certainty of outcomes, may be genetically related, and the disease trajectory can involve a deterioration in life quality over a number of years (Leedham & Meyerowitz, 1999). Much research has focused on cancer's impact on the individual, but when a parent of dependent children is diagnosed with cancer, the entire family is impacted, with children particularly vulnerable to psychological and psychosocial stress (Buchbinder et al., 2009; Harris & Zakowski, 2003; Huizinga et al., 2011; Morris et al., 2016; Semple & McCaughan, 2013). Specific population statistics regarding the number of people diagnosed with cancer whilst parenting dependent children are not available in Australia (Martini et al., 2019; Morris et al., 2019). Nevertheless, health-related statistics and previous studies support the notion that the prevalence of this phenomenon is significant.

In 2022, of the estimated 162,000 individuals to be diagnosed with cancer in Australia, over 17% were predicted to be aged between 20 and 54 years (AIHW, 2022). Further, women in Australia are having children later in life. For example, a comparison of birth rates in 2021 with birth rates recorded 30 years ago, indicates the birth rate of women aged 35-39 years has doubled over the period, and for women aged 40-44 years, the rate has nearly tripled (Australian Bureau of Statistics [ABS], 2022). Thus, many adult cancer patients may be parenting minor-aged children (aged under 18 years). Previous studies support this assertion. For example, a population-based study in the USA estimated that 2.85 million minor-aged children were living with a parent diagnosed with cancer (Weaver et al., 2010) and it has been estimated that 24% of adult cancer patients in the United Kingdom are parenting children aged under 18 years (Semple & McCaughan, 2013). Recent retrospective studies of Western Australian population, health and administrative data for the period 1982-2015 identified almost 26,000 pre-adolescent children and 58,000 adolescents and young adults, had a parent diagnosed with cancer during this period (Martini et al., 2019; Morris et al., 2019). CanTeen (2021), the Australian organisation for young people living with cancer, estimates that 58 young people learn of a parent's cancer diagnosis each day.

A cancer diagnosis for a parent of minor-aged children presents the parent, and their family, with multiple challenges (O'Neill et al., 2018). Parents are confronted with the challenge of coping with the unpredictable demands and threats of the illness and treatment, whilst continuing to nurture and support their children (O'Neill et al., 2018). Children are faced with disruptions to the usual routines and roles within the family, the absence of the parent due to illness treatment and side effects, and the threat of their parent's death (Finch & Gibson, 2009; Grant et al., 2016). By way of illustration, I offer this personal perspective. My interest in this phenomenon stemmed from a lived experience in my own family. In 2007, my first wife received an initial diagnosis of incurable metastatic breast cancer. At the time our two sons were aged 19 and 16 years. As parents, our approach towards incorporating the diagnosis into our family's way of life was entirely self-directed. We received no support or advice around the possible effect on our children and family from the medical professionals we encountered in the early stages of diagnosis and treatment, nor was our family structure recorded when registering my wife for oncology treatment. My wife wanted to protect our sons, consequently communication with them about her prognosis and treatment was limited to "good news", with any information about worsening results from scans and tests being withheld. My focus was very much on my wife's wellbeing and I expected the same from my sons. Thus, any behaviour which contradicted this "team" approach was not acceptable. This proved extremely problematic with our youngest son during the course of my wife's treatment, as he began acting out and creating stress within the family, particularly for my wife. My wife and I did not appreciate the developmental challenges faced by our adolescent son, and how such challenges could be intensified by having a parent with cancer. This also created difficulties for our older son, who took on the role of controlling his younger brother, carrying the burden of keeping much of his younger brother's behaviour secret from my wife and me. Further, our efforts to maintain a belief that all was well impacted communication between my wife and me. I felt reluctant to ask my wife how she was feeling emotionally, out of not wanting to upset her; she in turn felt distress at not being able to talk about her emotions, leading to feeling alone in her personal anguish. As I look back at these times, I can see how we could have dealt with things very differently within the family and mitigated much of the distress of that time. This experience was well over a decade ago, and through this research project I wanted to expand current understanding and awareness of what parents with cancer are experiencing now, how they and their families are responding, and what support they might need. I wanted to learn if the experiences of parents today are similar or different to the experience in my family and what has been reported in the literature. For my wife and me, learning of her cancer diagnosis was a telling moment in both our lives. For my sons, hearing the news was a moment they will never forget.

2 Aims, Objectives and Research Questions

My aims in conducting this study were to contribute new knowledge and understanding as to how parents and families are responding to the impacts of a parental cancer diagnosis, and determine if gaps exist in the support and guidance that parents receive in effectively managing such impacts. My objectives were to conduct semi-structured interviews with cancer patients who are parenting minor-aged children, transcribe and de-identify the interviews, thematically analyse the interview data using a coding procedure, and disseminate the findings by way of a thesis, published journal article and conference presentation. The research questions for this study were informed by my aims and are included below:

Primary Research Question

What is the experience of parents who have been diagnosed with cancer whilst parenting minor-aged children?

Secondary Research Questions

- What factors are associated with the impact a cancer diagnosis for parents of minor-aged children has on them and their families?
- What helps or hinders parents of minor-aged children and their families to effectively manage the impact of a parental cancer diagnosis?
- What perceptions do parents of minor-aged children have of the role played by oncology professionals in assisting parents navigate the familial effects of a parental cancer diagnosis?

3 Literature Review

This literature review offers an examination of the existing literature relating to the key aspects associated with the aims and research questions of this study. The first section provides an introductory descriptive overview of the development of systemic ideas and theoretical approaches towards individual and family counselling and therapy, and incorporates a review of the literature around the application of systemic ideas towards chronic illness within families. The second section offers a review of the literature relating directly to the phenomenon of parental cancer in families with minor-aged children. The review concludes with an examination of the literature around the role and experiences of oncology professionals when treating cancer patients who are parents of minor-aged children.

3.1 Family Dynamics – Theoretical Frameworks and Chronic Illness

Emerging in the mid-20th century, the systemic view of the family offered a new approach to individual and family counselling and therapy, and was grounded in the fundamental tenet that “the client is connected to living systems” (Corey, 2013, p. 435). Systemic principles in family therapy were underpinned by von Bertalanffy’s General Systems Theory, which challenged the dominance of the mechanistic and reductionist approach to understanding organisms and entities in isolation (Boerger-Knowles & Ridley, 2014; Goldenberg & Goldenberg, 2002; von Bertalanffy, 1950, 1972). von Bertalanffy advocated for the scientific investigation of systems as whole entities, and advanced the interdependence and interrelatedness of the components within systems, and systems’ constant interactions with the external environment and events (1950, 1972). von Bertalanffy (1950) argued that one could not understand the whole system by exploring components in isolation, nor understand the intricate relations of components by solely observing the system as a whole. General Systems Theory offered a paradigm for understanding all active systems across many disciplines, including behavioural and social sciences, and conceptualised a systemic approach towards understanding the interactive dynamics within the family unit (Goldenberg & Goldenberg, 2002; von Bertalanffy, 1972).

Much of the theoretical foundation for applying Bertalanffy’s systemic ideas to human relationships was provided by Bateson’s focus on the connected patterns and practices between interrelating family members (Goldenberg & Goldenberg, 2002; Wampler et al., 2020), “which reveal the family’s implicit rules, rituals and role assignments for living together" (Goldenberg & Goldenberg, 2002, p. 26). Bateson, a cultural anthropologist, was influenced by the mathematical concept known as cybernetics, referring to the investigation of feedback regulation within systems, and how such thinking could be extended towards understanding social practices (Goldenberg & Goldenberg, 2002; Stagoll, 2006). Cybernetics offered a shift from reductionist thinking around linear causality (A causes B), to an alternative idea of circular causality (A causes B *and* B causes A) (Stagoll, 2006; Wampler et al., 2020). In human terms, circular causality proposed the concept "that while we influence someone, we are simultaneously influenced by that person" (Reiter, 2018, p. 4) and represented a fundamental precept of the systemic approach to individuals and families (Robinson, 1993).

Bateson posited the capacity of systems to respond to feedback loops (a cybernetic term) in a self-corrective manner (Stagoll, 2006), in order to maintain balance, or "homeostasis" (Goldenberg & Goldenberg, 2002, p. 27). In cybernetic terms, a feedback loop is a means of system governance, feeding output information back to the source in order to amend, modify or regulate a system (Goldenberg & Goldenberg, 2002; Stagoll, 2006; Wampler et al., 2020). For a family where change has occurred and balance is threatened, circular feedback loops are generally activated by family members to return balance to the family (Goldenberg & Goldenberg, 2002). Bateson championed circularity in his work on the interpersonal patterns and processes underpinning communication and behaviour, and advanced a new vocabulary, in harmony with cybernetics and systemic thinking, that underlined the circular relationships between parts of the family system (Goldenberg & Goldenberg, 2002; Reiter, 2018; Stagoll, 2006). Early pioneers of systemic-focused therapies for individuals and families, such as Minuchin and the Milan group, used systemic and cybernetic ideas and language to develop foundational models and methods in the field of family therapy, all of which gave emphasis to the interpersonal characteristics of human difficulties (Boerger-Knowles & Ridley, 2014; Corey, 2013; Rockinson-Szapkiw et al., 2011; Wampler et al., 2020) and the understanding that "individuals were best understood in the contexts of their families and systems" (Rockinson-Szapkiw et al., 2011, p. 191).

The principles of Minuchin's Structural Family Therapy were developed in his work with young boys and their delinquent behaviours in the early 1960's (McAdams et al., 2016). Marking a distinct departure from the individualistic and intrapsychic approaches of the time, Minuchin recognised the socioeconomic and cultural factors affecting the boys' families, and sought to address the boys' individual behaviour by involving their families in therapy (Goldenberg & Goldenberg, 2002; McAdams et al., 2016; Wampler et al., 2020). Minuchin proposed that individual behaviour within families is governed by the structures and interactive characteristics of the family, thus the aim of his approach was to address the problematic issues within family structures, changing inoperative hierarchies and establishing strong boundaries between family sub-systems (McAdams et al., 2016; Minuchin, 1974; Wampler et al., 2020).

Minuchin posited that family structures can be observed through the interactive patterns and processes between family members, and that when a family structure is altered, the positions of individuals within the family are also altered (Wampler et al., 2020). Events affecting individuals within a family will impact upon the family unit as a whole, generating compensatory change in other family members (Boerger-Knowles & Ridley, 2014; Corey, 2013; McGoldrick & Carter, 2001), such as individual family members focusing on and acting out the family's stress (Minuchin, 1974). The idea of compensatory change is grounded in the concept of reciprocity: relationships within families operate in established, repetitive and circular patterns (Boerger-Knowles & Ridley, 2014; McGoldrick & Carter, 2001). Change involving an individual can disrupt the balance within families and, in the case of non-normative change, such as a parental cancer diagnosis in a family with young children, family members may suffer major destabilisation (Cohen, 2009). For example, a parent diagnosed with cancer may be absent from the family due to hospitalisation or treatment, requiring an adolescent daughter or son to take greater responsibility for household functions, disrupting the child's developmental struggle for independence, leading to tension between parent and child (Harris & Zakowski, 2003). Minuchin (1974) proposed that in order for a family to continue as a functioning system in the face of destabilising change, the family must adapt in ways that meet the challenge of change whilst maintaining permanency and consistency for family members.

Influenced by Bateson and systemic ideas, four Italian psychiatrists in Milan established Systemic Family Therapy: Boscolo, Cecchin, Prata, and Selvini-Palazzoli (Goldenberg & Goldenberg, 2002; Reiter, 2018). Generally referred to as the Milan model, this approach has been acknowledged as perhaps the most systemically oriented approach in family therapy (Wampler et al., 2020). The Milan group posited that individual impairment was supported by a family's need for equilibrium; thus, therapeutic work was directed towards detecting how each family member related with the presenting problem and participated in the preservation of the family's homeostasis (Reiter, 2018; Wampler et al., 2020).

In the Milan model, the metaphor "family games" (Reiter, 2018, p. 199) was given to the strategies and laws by which family members grapple with each other whilst jointly continuing unrecognised connections in order to regulate each other's behaviour (Goldenberg & Goldenberg, 2002; Reiter, 2018; Wampler et al., 2020). For Milan model therapists, "the problem creates the system" (Reiter, 2018, p. 199) and the goal of therapy was to decipher the inflexible rules of family games and encourage a move towards more adaptable new rules, using strategic intervention techniques (Goldenberg & Goldenberg, 2002; Wampler et al., 2020). At a fundamental level, the Milan group applied a counter-paradoxical approach to clinical practice, in order to illuminate “the relational deceit that captured family pathology: families fall into paradox since they are unable to abandon the emotional field” (Barbetta & Telfener, 2021, p. 5). A central intervention technique, positive connotation, involved a Milan therapist’s reframing of a family member’s behaviour, viewed as “negative” by the family, as “positive or good” (Goldenberg & Goldenberg, 2002, p. 95). The motives and intents informing the pathologised family member’s behaviour was presented to the family as having a caring and vital function for the wellbeing of other family members and the stability of the family (Goldenberg & Goldenberg, 2002; Wampler et al., 2020); thus offering a counter paradoxical redefinition where “The so-called identified patient was considered the family member whose sacrifice maintained the unity of the family” (Barbetta & Telfener, 2021, p. 5).

The Milan group also devised the technique of circular questioning, in which questions are asked of each family member and framed to underscore different opinions and experiences of the same episode or situation (Goldenberg & Goldenberg, 2002; Wampler et al., 2020). Rather than simply appeals for direct information, questions were seen as instruments for “perturbing” the family system, providing feedback to the family system, highlighting differences in perception, and prompting the family to begin seeing itself through a systemic lens (Barbetta & Telfener, 2021, p. 5; Goldenberg & Goldenberg, 2002; Wampler et al., 2020). For example, Marley (2004) discussed the application of the Milan model in work with families living with an individual member’s mental health illness, such as schizophrenia. Marley (2004) proposed that the family’s primary focus on the individual’s pathology can become the dominant mode of functioning within the family. In such a scenario, a Milan therapist’s use of circular questioning to “shift the focus to the family system” would not be employed for the purpose of “blaming the family” for the family member’s pathology; rather, questioning is applied to illuminate how the family system promotes or inhibits the family's capacity to cope with the illness (Marley, 2004, p. 72). The Milan model has transitioned since the original development of the approach, as some of the proponents of the model became influenced by post-modern ideas that challenged the fundamental systemic frameworks informed by General Systems Theory and cybernetics (Goldenberg & Goldenberg, 2002; Reiter, 2018). The evolution of these ideas is further reviewed on page 17.

Representing a point-of-difference from other conventional approaches to family therapy, Bowen's Family Systems Theory emphasised a multigenerational perspective in understanding the problems occurring in families (Corey, 2013; Reiter, 2018). Bowen viewed the family as "an emotional unit", and the relational and emotional processes within a family can both increase and decrease anxiety in each member of the family (Gottlieb, 2019, p. 198). Bowen asserted that these processes are conveyed across multiple generations of the family, and can be observed in the ways a family reacts in the face of exceptional challenge, such as a parent's cancer diagnosis (Corey, 2013; Gottlieb, 2019; Reed, 2019) or as Bowen termed, an "Emotional Shock Wave" (Bowen, 2019, p. 8).

How ancestral families have reacted to emotional shock waves in the past can provide a historical context to the way in which families react emotionally and relatedly in the present day (Reed, 2019). For example, communication may be "open", whereby family members are encouraged to talk about their feelings and thoughts; or "closed", where freedom of expression is restricted in order to protect family members from anxiety and distress (Bowen, 2019, p. 4). The challenge for members of the family in such situations is to develop insight and emotional regulation in order to navigate a sensitive equilibrium between independence and closeness in relationships with the family, what Bowen called "differentiation" (Gottlieb, 2019, p. 196). In families where there is a paucity of differentiation, decisions are driven by apprehension and insecurity (Gottlieb, 2019). Family members who can offer a considerate presence and connection with the family, while maintaining humble and accountable control of self, can contribute to a more open and less anxious family system (Reed, 2019).

As theoretical development in family counselling and therapy evolved, post-modern, feminist and multicultural practitioners began to challenge what were considered limitations in traditional family therapy frameworks (Corey, 2013; Wampler et al., 2020). Traditional models were criticised for being founded in theories and concepts that did not consider the contextual, social, political, and historical factors associated with family dysfunction, such as economics, ethnicity, culture, gender and power, family structure, support networks, and social norms and expectations; all factors contributing to the healthy functioning of family systems (Goldenberg & Goldenberg, 2002; Wampler et al., 2020). Moreover, some traditional models were criticised for the directive and observing stance assumed by the therapist, outside the family system, and the notion that the therapist is responsible for promoting change in the family; a concept that has been termed first-order cybernetics (Corey, 2013; Wampler et al., 2020). In contrast, new approaches evolved which were grounded in in the notion of second-order cybernetics, where the therapist, aware of the power inherent in their role, joins the family and becomes part of the system, adopting a decentred and curious stance, and works collaboratively with the family to help change occur (Carr, 1998; Corey, 2013; Goldenberg & Goldenberg, 2002). Narrative Therapy, developed by White solely and in association with Epston, has been described as one of the most significant of these post-modern family therapy approaches (Carr, 1998; Corey, 2013). White and Epston held the social constructivist view that an objective reality or “truth” does not exist; rather, knowledge and experience is contextual and socially constructed (Goldenberg & Goldenberg, 2002, p. 96), and their ideas were informed by the work of a number of social theorists, including Foucault and Bateson (Besley, 2008; Dumaresque et al., 2018; White & Epston, 1990).

White and Epston countered traditional psychological and medical models, which they saw as pathological and oppressive, by seeking to employ the energy of conversation in order to understand lived experience and uncover new possibilities for people in responding to suffering (Besley, 2008; Dumaresque et al., 2018). White and Epston posited that authentic lived experience is suppressed and marginalised by dominant stories of power that form alternative and ill-fitting narratives of people's lives (Besley, 2002; Carr, 1998; White & Epston, 1990). The narrative therapist employs "externalising language" (Besley, 2002, p. 128) to locate the problem external to the person and challenge the power-based story which has sustained the problem (Carr, 1998; White & Epston, 1990). Using imaginative and questioning dialogue from a stance of curiosity, the therapist opens space for alternative stories that are closer to, or fit with, lived experience (Besley, 2002; Carr, 1998), and by illuminating "sparkling moments" when the problem was absent, "people are assisted to find unique outcomes and alternative ways in which they prefer to describe themselves" (Besley, 2002, p. 128). For example, Abdalla and Novis (2014) described a narrative approach towards therapy with families dealing with a family member's chronic illness, such as cancer. Abdalla and Novis (2014) utilised a set of reflective tasks, metaphor, and whole of family discussions, to externalize the chronic illness as an "unexpected visitor" who arrives uninvited, expanding the ways family members have responded to the circumstances of the visitor, and challenging the family to search through their "pantry of life" to uncover unrecognised resourcefulness, abilities, and strength (p. 102).

In the field of chronic illness, a number of systemically oriented studies have been conducted to assess the experience, awareness, and needs of patients and their families across a range of chronic health challenges and settings, including stroke, neurocognitive impairment such as early onset dementia and brain injury, palliative care, mental health diagnoses such as autism, other somatic illnesses, and cancer (Årestedt et al., 2014; Mehta et al., 2009; Östlund et al., 2016; Prendeville & Kinsella, 2019; Roach et al., 2015; Rolland, 2005, 2017). Such studies support the concept of embedding a family focus in the treatment of chronic illness, highlighting the importance of interactions between patients and health care professionals. Moreover, research suggests that how family members react to a confronting change such as a parental cancer diagnosis may in turn have a significant effect on the wellbeing of the ill parent (Boerger-Knowles & Ridley, 2014; Hartmann et al., 2010).

A meta-analysis of the literature conducted by Hartmann et al. (2010) underscored the junction of family functioning and health outcomes for chronic disease sufferers. Hartmann et al. (2010) proposed that families can influence the course of a family member's chronic illness in two specific ways: how the family copes emotionally with the illness can affect the patient's physical wellbeing, and the ways in which family members engage in practical support for patients can influence patient adherence to treatment and self-care practices. Hartmann et al. (2010) identified 52 randomised clinical trials which involved evaluation of family-focused interventions for adult chronic disease sufferers, delivered by health care professionals. The trials evaluated patient physical and mental health, and the health of other family members, and all trials included a control group receiving standard disease treatment. Hartmann et al. (2010) found that including family-focused interventions in the treatment of chronic illness resulted in significantly improved health outcomes for patients and family members across all health measurements, compared with comparison groups. Hartmann et al. (2010) categorised the interventions into two main types: interventions that provided education or psycho-education to patients and families about the illness and its impact on the family, promoting family awareness and involvement in illness management, and relationship-focused interventions intended to augment family cohesion and reduce relationship stress.

DiMatteo (2004) and Hatchett et al. (1997) suggested that the support of social networks is a significant interpersonal factor in determining a person's ability to live with chronic illness. Supportive social networks encourage illness sufferers to adhere to treatment regimens and self-care, by promoting confidence, self-efficacy, and cushioning the psychological stress of illness, whilst continuing to function at a family and social level (DiMatteo, 2004; Gallant, 2003). Conversely, a person's adjustment to chronic illness may be compromised when the extent of the illness and its possible consequences are trivialised by significant others, or the person perceives an inability to meet the expectations of family and friends, potentially leading to distress and social isolation (Hatchett et al., 1997). Adams et al. (2017) referred to cancer-related loneliness as a perception of isolation and being constrained by social behaviours, such as disapproval and rejection when seeking to discuss illness-related apprehensions and existential concerns with others. Social expectations around gender roles may also add complexity to a cancer diagnosis. Gibson et al. (2018) investigated women's relational experiences of care from partners, family and friends following a cancer diagnosis, and found that women continued to fulfill the traditional role of caregiver and emotional supporter of their partners and children, minimising their own emotional and care needs. Gibson et al. (2018) asserted that the experience of cancer within relationships should be considered within a context of socially constructed gender roles, and the dynamics at play in relationships. Thus, the give and take of interactions and adjustments within families in the face of destabilising change makes the family "our greatest potential resource as well as our greatest potential source of stress" (McGoldrick & Carter, 2001, p. 283).

When interviewing the participants in this study, the concepts of hope and resilience emerged as important coping factors for the participants as they faced their cancer challenges. This has encouraged further reading for this literature review, in order to convey an understanding around the notions of hope and resilience. Some aspects of this additional reading related to the role of health care professionals in the cultivation of hope and resilience for cancer patients. Whilst the role of health care professionals may not directly relate to the topic of this section of my literature review, I have included it here as the relationships cancer patients have in their external environment, including with health care professionals, are central in the development of individuals' hope, resilience and wellbeing (Wang et al., 2022).

Research into the concept of hope has been a challenging endeavour for researchers, such is its ethereal character, its fusion of immateriality and actuality, and its interpretative nature (Chi, 2007). The literature contains many definitions of hope. When used as a noun, hope is "a feeling of expectation and desire for something to happen" (McClement & Chochinov, 2008, p. 1170). Similarly, O'Hara (2011) described the action of hope as "desiring, of having confidence, of believing or trusting in someone or something" (p. 324). Thus, hope is aspirational and future-focused in nature, and many studies have found that hope serves as a valuable means of coping and enrichment of life quality for cancer patients (Lichwala, 2014; McClement & Chochinov, 2008), regardless of the stage of illness progression (Chi, 2007). Indeed, studies in end-of-life care have identified the central role that hope plays in the psychosocial health of advanced cancer patients (McClement & Chochinov, 2008), whilst appreciating that "true hope is grounded in reality" (O'Hara, 2011, p. 325). In a study of 17 separate pieces of literature pertaining to the concept of hope in terminally ill people, Johnson (2007) identified 10 central qualities associated with the enhancement of hope, including a positive attitude to life and new priorities in living; personal qualities, such as inner strength, resolve, and a capacity for acceptance; spirituality; being comfortable and free from pain; helpful and caring behaviours from others; and, loving relationships with family and friends (Johnson, 2007). Similar findings have emerged in other studies involving cancer patients and hope. In a primary review of nursing research literature concerning hope in cancer patients, Chi (2007) identified a number of factors associated with the cultivation and preservation of hope, with the most common factors being the quality of close relationships and being able to talk to others; religion and spirituality; living in the present moment; symptom and pain management; and having a positive attitude.

The quality of cancer patients' interpersonal relationships is central to the cultivation of hope (Johnson, 2007). Beyond the loving bonds with family and friends, Johnson (2007) asserted that the preservation of hope was underpinned by "honest relationships with oncologists, doctors and nurses" (p. 455). The literature supports the notion that respectful and reciprocal communication between doctor and cancer patient, and a collaborative approach to decision making around clinical treatment, enhances patients' psychological wellbeing (Barnes et al., 2000; Lee et al., 2002). Further, hope and the quality of interpersonal relationships are closely related with cancer patients' resiliency and their capacity to cope with the diagnosis and the physical effects of treatment (Lichwala, 2014; Rustøen et al., 2010; Wang et al., 2022). Wang (2022) defined resiliency as the "ability to adapt in the face of adverse external events" (p. 1), and resiliency helps cancer patients recover and sustain their health and general wellbeing, despite the trauma of diagnosis and physical impact of cancer treatment. Health care professionals therefore play a critical role in encouraging qualities of hope and resilience for cancer patients, by establishing an effective and collaborative clinical relationship with patients, underpinned by honest, empathic, and knowledgeable communication (Butow et al., 1996; Lee et al., 2002; Lichwala, 2014; McClement & Chochinov, 2008). On the other hand, difficult communication experiences with health care professionals for cancer patients is correlated with increased distress and low mood, ineffective pain control and difficulties coping, diminished life quality, and a sense of hopelessness (Lichwala, 2014; McClement & Chochinov, 2008).

3.2 Impact of Parental Cancer

Over the past three decades, researchers have given considerable attention to the familial impact of parental cancer (Semple & McCaughan, 2013), with many studies investigating the impact of parental cancer on minor-aged children (Huizinga et al., 2011). Several meta-analyses of the literature have identified inconsistencies and contradictions in results: children of parents with cancer have been reported as demonstrating inferior, comparable and superior functioning than norm or control groups (Harris & Zakowski, 2003; Morris et al., 2016). The literature supports the notion that child functioning when a parent has cancer is strongly mitigated by the ways in which the parent and family adapt to and cope with the diagnosis, rather than particular characteristics of the illness (Buchbinder et al., 2009; Morris et al., 2016). Accordingly, psychological distress in parents, such as depression and anxiety, altered parenting practices due to absence of the ill parent, and restricted family communication, are associated with increased child distress (Buchbinder et al., 2009; Hailey et al., 2018). Furthermore, when a parent has cancer, their dependent children are at an elevated risk of psychological and psycho-social impairment, due to changes in normal family routines and roles, and the worry around the seriousness of their parent’s illness (Ellis et al., 2017).

Several domains of negative reactions by children have been highlighted in the literature. These include changes in mood, evidenced by crying, anger, fear and anxiety, and depleted self-esteem; mediocre academic performance and poor concentration; somatic complaints, such as stomach aches, loss of appetite and sleep disturbances; and behavioural and social changes such as acting out, withdrawal from peers and friendships, and a loss of interest in normal activities (Harris & Zakowski, 2003; Huizinga et al., 2011; Morris et al., 2016; Semple & McCaughan, 2013; Visser et al., 2004). Contradictions exist in results for school-aged children (aged 4 to 11 years), with several studies identifying increased emotional problems, whilst other studies found similar or superior functioning compared with peers (Huizinga et al., 2011; Visser et al., 2004). There was evidence of more somatic complaints compared with peers, but little evidence of social withdrawal or reduced social competence (Huizinga et al., 2011; Visser et al., 2004). For adolescent children (aged 12 to 18 years), findings identified more emotional problems, stress response symptoms and somatic complaints compared with peers, but no marked difference in social functioning (Huizinga et al., 2011; Visser et al., 2004). Adolescent daughters of a parent with cancer have been commonly reported to have exhibited the highest levels of anxiety, depression, intrusive thoughts and avoidance, particularly when their mother has cancer (Harris & Zakowski, 2003; Huizinga et al., 2011; Visser et al., 2004). On the other hand, in a study of distress in adolescent children of cancer patients compared with a control group of adolescents with healthy parents, Harris and Zakowski (2003) found that adolescents in the ill parent group measured lower for stress response symptoms than adolescents in the control group; the authors concluded “Adolescence is an extremely distressing time whether or not a parent has cancer” (p. 179).

Long-term negative effects reported by adults who were minors when their parent was diagnosed include a concern for their own health due to genetic risk factors associated with cancer, leading to anxiety and feelings of helplessness; a pessimistic outlook on life and relationships, and a general mistrust of people; and impaired personal relationships with the ill parent and extended family members (Wong et al., 2009). However, the literature has also recognised the potential for long-term positive outcomes following an experience of parental cancer as a child (Levesque & Maybery, 2012; Wong et al., 2009). Adults who were minor-aged when their parent was diagnosed have reported a positive enhancement to character development, such as increased maturity and compassionate awareness; a greater appreciation for life and positive changes in health related behaviours; a strengthening of family and personal relationships; and an interest and involvement in cancer and community issues (Huizinga et al., 2011; Levesque & Maybery, 2012; Wong et al., 2009).

Limitations associated with research in parental cancer have been acknowledged in the literature and must be considered when reviewing study results. These include low sample sizes and difficulties in participant recruitment due to the sensitive nature of the subject matter (Harris & Zakowski, 2003; Huizinga et al., 2011; Schmitt et al., 2007; Wong et al., 2010). Also, in studies of child functioning, parental views often describe more positive perceptions than those of their children (Visser et al., 2004). On the issue of parent gender and cancer type, researchers have identified a high proportion of mothers with breast cancer in the literature (Huizinga et al., 2011; Schmitt et al., 2007; Visser et al., 2004). Notwithstanding these reported limitations, it is acknowledged in the literature that the children of parents with cancer are encumbered with significant challenges and stressors, and are at increased risk of psychological impairment (Morris et al., 2016).

A number of qualitative studies have been conducted in various countries and settings, into the experiences of parents who have been diagnosed with cancer (Asbury et al., 2014; Barnes et al., 2000; Buchbinder et al., 2009; Fisher & O'Connor, 2012; Lalayiannis et al., 2018; O'Neill et al., 2018; Park et al., 2017; Rashi et al., 2015; Schiena et al., 2019; Semple & McCaughan, 2013; Turner et al., 2007a). Studies have identified key factors around family communication and the need to maintain normalcy within families, and have highlighted the difficulties faced by parents in balancing the role of parent with being a cancer patient (Rashi et al., 2015). For mothers with cancer, a need to protect their children has been found to inhibit honest communication with other family members and taking the time to provide for their own psychological and psychosocial care (Asbury et al., 2014; Lalayiannis et al., 2018). For fathers, being diagnosed with cancer has undermined self-perceptions around being the economic provider for the family, and challenged fathers to redefine their identity within the family (O'Neill et al., 2018). Further, partners of the parent with cancer may be overwhelmed by the additional demands placed upon them, particularly in traditionally gendered relationships where support within the family is primarily provided by the mother (Gibson et al., 2018; O'Neill et al., 2018).

Throughout the literature, honest and open patterns of communication and emotional expression within families dealing with parental cancer, at a developmentally appropriate level when communicating with children, has been consistently associated with enhanced family functioning (Asbury et al., 2014; Barnes et al., 2000; Buchbinder et al., 2009; Finch & Gibson, 2009; O'Neill et al., 2018; Semple & McCaughan, 2013; Sinclair et al., 2019; Turner et al., 2007a; Visser et al., 2004). Nevertheless, some studies have reported that many children are not told when a parent has a severe life-threatening illness such as cancer, and this has correlated with reduced family unity and low parental wellness (Barnes et al., 2000; Wong et al., 2010). Parents have expressed a lack of confidence, skills and knowledge with regards to whether to inform children, what to tell them, and how to tell them, which increased their own stress in response to a cancer diagnosis (Asbury et al., 2014; Barnes et al., 2000; Schiena et al., 2019; Semple & McCaughan, 2013; Wong et al., 2010). Wong et al. (2010) proposed that the information parents offer to, or conceal from, children regarding parental cancer, intending to alleviate children’s anxiety, may have the paradoxical effect of promoting the opposite perception in children: the avoidance of illness-specific communication often adds to children’s anxiety. According to Finch and Gibson (2009), adolescents expressed that honest communication and involvement in their parents’ treatment was essential for family cohesion, and a number of studies have advocated for parents to receive guidance around open and age-appropriate communication with children after a diagnosis of cancer (Barnes et al., 2000; Finch & Gibson, 2009; Fisher & O'Connor, 2012; Huizinga et al., 2011; O'Neill et al., 2018; Turner et al., 2007a). However, recent studies conducted in other countries have suggested that parents diagnosed with cancer have relied more on their own perceptions, instincts and resources when faced with the challenges of telling their children and incorporating cancer into family life (Lalayiannis et al., 2018; Rashi et al., 2015).

Rashi et al. (2015) emphasised the tangible challenges faced by parents with cancer, and highlighted parents’ reliance on their social networks for psychosocial support. Parents indicated the need for more practical and tailored family-focused medical support, specific to parents with young children, such as convenient appointment times, and greater access to transport and parking (Rashi et al., 2015). Whilst family-focused support was offered to parents by medical professionals, Rashi et al. (2015) suggested the support often did not meet the unique needs of parents and their families. Rashi et al. (2015) also reported greater parental competence and agency in how to communicate with their children about cancer, which contradicted findings in previous studies. This was corroborated by Lalayiannis et al. (2018), who reported that mothers faced with telling their children about a diagnosis of advanced breast cancer felt an intuitive awareness around when, what and how to tell their children. This could have been related to the illness being a secondary diagnosis, having perhaps already been incorporated into family life, though participants expressed they did not require professional support for themselves, preferring to rely on their own judgement and knowledge of their children (Lalayiannis et al., 2018). Participants in the study by Lalayiannis et al. (2018) stated that professional support would be best placed if it was tailored specifically for their children, rather than themselves.

3.3 Role of Oncology Professionals

The literature consistently advocates for parents with minor-aged children to receive support and education around the impact on their families following a diagnosis of cancer (Asbury et al., 2014; Barnes et al., 2000; Finch & Gibson, 2009; Fisher & O'Connor, 2012;

Turner et al., 2007a). Further, medical staff involved in the treatment and care of parents have been acknowledged as being ideally placed to raise parents' awareness as to the potential effects on parents' families (Arber & Odelius, 2018). The provision of psychosocial support for adult cancer patients is an emerging discipline, leading to the development of clinical practice guidelines in many countries, including Australia (Turner, 2015). Such guidelines are designed to support the integration of psychosocial care into general cancer treatment practice; however, barriers preventing this integration continue to exist in primary health settings (Turner, 2015). Over recent years, researchers have investigated the barriers which may prevent health care professionals from providing support and education to parents with cancer. Subsequently, a number of factors have been identified which contribute to the difficulties experienced by health care professionals, including practical restrictions, such as over-burdened clinical environments (Dencker et al., 2017) and personal barriers, such as inadequate knowledge and skills when caring for a parent with cancer (Turner et al., 2007b). To this end, educative interventions for health care professionals have been developed and trialed, such as Turner et al. (2009) and Grant et al. (2016), with encouraging results. However, Fallowfield et al. (2002) questioned whether skills and knowledge acquired through training are effectively transferred into ongoing clinical practice.

Qualitative studies have been conducted into the experiences, perceptions and concerns of frontline oncology staff when caring for parents who have cancer and minor-aged children (Arber & Odelius, 2018; Dencker et al., 2017; Turner et al., 2007b). Oncology nurses are prominent in the relevant literature, as the clinical structure of cancer treatment services often means nurses spend more time with cancer patients and are therefore more available (Fisher & O'Connor, 2012; Turner et al., 2007b). Turner et al. (2007b) conducted focus groups and telephone interviews with 29 oncology nurses in Queensland, Australia, to understand nurses' insights into their provision of psychosocial support to parents with advanced cancer diagnoses and minor-aged children. Turner et al. (2007b) found that whilst nurses saw psychosocial support as an essential part of their position, the emotional experience of caring for patients dealing with cancer whilst parenting dependent children, coupled with professional factors, led to self-doubt and personal anguish.

Turner et al. (2007b) reported that nurses expressed several concerns, including uncertainty in addressing family issues with parents, believing that intervention may cause further distress for parents and make things worse; difficulties in being parents themselves and empathising with patients and their children, imagining how they might experience having advanced cancer and a young family; and carrying the emotional burden of caring, particularly if they developed close relationships with patients and families who faced an uncertain future. Participants in the study by Turner et al. (2007b) also reported several professional factors, including inadequate training and professional recognition of how parental cancer may impact families; lack of knowledge around the developmental life stages of children, leading to a lack of confidence in advising parents how best to communicate with their children about advanced cancer; a lack of specialised support staff, such as psychologists, for referral of parents and their families; the general work environment, where staff shortages, time pressures and negative perceptions around psychosocial care from senior clinicians impeded nurses in providing family-focused care to patients; and absence of clinical supervision or opportunities to debrief with colleagues when feeling overwhelmed or distressed by the emotional burden of care.

The incurable nature of advanced cancer intensifies the challenges faced by parents and their families, compared with the challenges presented by early-stage cancer, thus increasing the difficulties for oncology professionals in providing psychosocial care (Check et al., 2017). Nonetheless, lack of professional training, and workplace culture and pressures, are universal aspects regardless of cancer type or illness trajectory. Turner et al. (2007b) proposed that, in addition to a greater focus on knowledge and skills development for staff, oncology care settings must also consider team structures and relationships, and staff attitudes towards psychosocial and family-focused care. The study by Turner et al. (2007b) utilises preliminary data collected approximately 18 years ago; hence it is appropriate to consider more current research of a similar nature.

Arber and Odelius (2018) also used qualitative focus group methods to explore the experiences of oncology and palliative care nurses caring for parents who have cancer and minor-aged children. In this study, 12 nurses from a single acute cancer setting in the United Kingdom participated in two focus group sessions. Arber and Odelius (2018) identified themes consistent with the earlier findings reported by Turner et al. (2007b). In particular, participants described the emotional challenge of supporting parents with cancer whilst imagining themselves being in a similar situation (Arber & Odelius, 2018). Specifically, female nurses who are mothers reported identifying with female cancer patients of similar ages, or the children of patients who are similar in age to the nurses' own children. Such identification was described as both emotionally challenging and distressing by some nurses, and a healthy means of coping with the family situation by others. Participants also described uncertainty and a lack of confidence in discussing family issues with parents, thus leaving any interactions to be instigated by direct questions from parents. Participants identified a lack of training and knowledge with regards to child developmental stages and not knowing how to advise parents about age-appropriate communication with their children about cancer. Participants highlighted the importance of peer support in promoting self-care, reassurance, and learning. In addition, it was noted by participants that there were no policies or practices devoted to the screening and identification of patients' family situations, within the clinical setting. Thus, nurses generally identified patients being parents of minor-aged children through ad-hoc interactions and encounters (Arber & Odelius, 2018). A lack of appropriate screening and family information is reported in the literature. Schmitt et al. (2007) described a collaborative study between a child psychiatry clinic and an adult oncology clinic both situated within a university hospital in Finland. The researchers' task of identifying cancer patients who were parenting young children was protracted, as patients' family information was not recorded by the oncology clinic. "The oncology clinic did not even know if their patients had children or not" (Schmitt et al., 2007, p. 427).

Inadequate recording and awareness of cancer patients' family situations is also identified by Dencker et al. (2017) as a factor in inhibiting the provision of family-focused support to patients suffering serious illness. Dencker et al. (2017) conducted qualitative semi-structured interviews with nine doctors and 15 nurses working within three hospital wards in Denmark, to explore the emotional and practical impediments experienced by the participants when faced with seriously ill patients who are parenting minor-aged children. Dencker et al. (2017) reported similar findings to those reported earlier. Dencker et al. reported other practical impediments, including the "professional code", inadequate staffing and time constraints whereby priority is given to the provision of physical care for patients, alongside insufficient or non-existent training, leading to a lack of confidence in speaking with patients about children and family issues (2017, p. 2164). Some doctors reported using an approach around maintaining a professional detachment from patients and their family circumstances, serving to avoid or cope with personal distress and retain a professional focus on providing accurate medical care (Dencker et al., 2017). Consistent with the position of Turner et al. (2007b), Dencker et al. (2017) argued that workplace culture and structure need to align with the concept of psychosocial care for seriously ill parents of minor-aged children.

A number of quantitative and mixed methods studies have focused on development, testing and evaluation of educative interventions for oncology professionals and related multidisciplinary professionals, involved in the cancer care of parents with minor-aged children, such as Grant et al. (2016), Semple et al. (2017) and Turner et al. (2009). Interventions included a self-directed educational manual for oncology nurses caring for parents with advanced cancer, complimented by a one-day communication skills workshop (Turner et al., 2009; Turner et al., 2008); a 3-day programme for health care professionals, utilising family systems and child development theories to address the impact of parental cancer on families (Grant et al., 2016); and a brief (less than 1hour) education session targeting frontline oncology staff, designed to improve staff confidence in addressing the impact of parental cancer with patients and families (Semple et al., 2017). Two of these interventions were conducted in the United Kingdom, the other in Queensland, Australia. In each study, post-intervention evaluations were completed by participants and these evaluative outcomes affirmed improvements in confidence, skills, and knowledge regarding parental cancer and families. However, whilst many participants expressed an intent to incorporate learnings into day-to-day clinical practice, some participants expressed concerns as to their capacity to transfer their learning into practice, or to retain the knowledge provided in the interventions (Grant et al., 2016; Semple et al., 2017). The effectiveness of the interventions was not corroborated with patient experiences within the studies identified (Grant et al., 2016; Semple et al., 2017), and within the literature parents with cancer have reported a disconnect between specific psychosocial interventions provided in medical settings and their unique parenting needs (Rashi et al., 2015). Further, the interventions have only been subjected to pilot testing; thus, there is an absence of longitudinal evidence as to the effectiveness of the interventions (Semple et al., 2017). Finally, self-reported confidence and knowledge does not necessarily reflect a measure of aptitude in providing psychosocial care (Fallowfield et al., 2002).

3.4 Conclusion

Over more than 3 decades, many studies have been conducted into the familial effects of parental cancer in various countries, with researchers giving particular attention to the risk of psychological impairment for minor-aged children (Huizinga et al., 2011; Semple & McCaughan, 2013). Qualitative researchers have studied the phenomenon through the lived experiences of parents diagnosed with cancer, including specific aspects such as family communication and identity (Asbury et al., 2014; Finch & Gibson, 2009; Fisher & O'Connor, 2012; O'Neill et al., 2018; Park et al., 2017; Rashi et al., 2015; Schiena et al., 2019). The research focus on parental cancer and its impact on the family has consistently identified the unique challenges faced by parents, in balancing the roles of parent and cancer patient (Rashi et al., 2015). For parents with cancer, the need to protect children can inhibit family communication and adherence to self-care and psychological support, and the illness may challenge ill parents to redefine their identity within the family (Asbury et al., 2014; Lalayiannis et al., 2018). Partners of the ill parent may be overwhelmed by the additional demands placed upon them (Gibson et al., 2018; O'Neill et al., 2018), and children may be impacted by altered parenting practices, routines and roles, and worrying about the seriousness of their parent’s illness (Buchbinder et al., 2009; Ellis et al., 2017; Hailey et al., 2018).

From the literature review, it would appear that the ability of parents to cope physically and emotionally with the cancer illness and its treatment, and the promotion of open communication and coping strategies that integrate cancer within family life, are key variables for promoting family cohesion and protecting children from short and long-term impairment. Further, whilst increased awareness of the familial impact of parental cancer for health care professionals has been advocated in the literature (Arber & Odelius, 2018), it would seem gaps remain between the provision of family-focused support in medical settings, and the actual needs of parents and their families. As discussed in the literature review, systemically-oriented theoretical approaches to individual and family counselling may be useful in considering how a parent's cancer diagnosis may impact both the parent and the family. Notwithstanding the research attention given to parental cancer, there is a dearth of qualitative investigations within an Australian context, related to the lived experiences of parents diagnosed with cancer whilst parenting children aged under 18 years. Thus, this study offers a current investigation as to how parents of minor-aged children experience cancer, adding to the body of research into parental cancer.

4 Research Design

4.1 Paradigm

In considering the primary research question "What is the experience of parents who have been diagnosed with cancer whilst parenting minor-aged children?" this study was informed by an interpretivist/constructivist research paradigm. The constructivist philosophy contends that individuals seek to subjectively understand the world as they see it, and create meanings of their unique experiences (Braun & Clarke, 2013; Creswell & Poth, 2018). My purpose in conducting this study was aligned with constructivist philosophy, in that I sought to explore and understand the intricate domain of lived experience from the viewpoint of the study participants (Creswell & Poth, 2018; McChesney & Aldridge, 2019). Further, to gain understanding as to the participants' experiences of being a parent with cancer, and to address the research questions, required my interpretive engagement with the participants' subjective knowledges and descriptions, in order to inductively generate themes of meaning (Creswell & Poth, 2018; McChesney & Aldridge, 2019). As White and Epston asserted, "since we cannot know objective reality, all knowing requires an act of interpretation" (White & Epston, 1990, p. 2). I also recognised that an interpretive pursuit of understanding the participants' lived experiences would be a socially constructed endeavour, incorporating the interactions between the participants and myself, and my own subjective contribution to the overall research activity (Braun & Clarke, 2013; McChesney & Aldridge, 2019). My interpretivist/constructivist stance in approaching the phenomenon of parental cancer was consistent with the primary research question and the purpose of this study, and reflected "the interpretivist principle that *understanding* (rather than explaining, generalising or critiquing) is the fundamental aim of research" (McChesney & Aldridge, 2019, p. 230).

4.2 Methodology

Given the exploratory nature of my purpose in undertaking this study, and in harmony with the paradigm informing my research endeavour, I chose a qualitative mode of enquiry. The purpose of my study was best served by a qualitative undertaking, as qualitative research is an interpretive approach that seeks to gain understanding of contextually based meaning, rather than generalisable knowledge (Braun & Clarke, 2013; Creswell & Poth, 2018). My approach to research methods aligned with the characteristics of a qualitative study, as defined by Creswell and Poth (2018), including the sensitive and naturalistic collection of data, and an inductive data analysis procedure that identified emerging patterns and themes, resulting in a written presentation that embraces "the voices of participants", a comprehensive interpretation and discussion of the phenomenon, and the significance of the study for further research (p. 8).

Qualitative research supports a flexible approach to research methods (Braun & Clarke, 2013), hence my study design and methods were impacted by ideas and processes founded in phenomenological and grounded theory approaches, both of which are common in qualitative research (Smith et al., 2009). Informed by phenomenological principles, in this study I sought to meticulously investigate the conscious and subjective experiences of people specifically recruited because they had experienced the phenomenon of parental cancer (Eatough & Smith, 2017; Giorgi & Giorgi, 2008; Smith et al., 2009). Phenomenological principles also underpinned the disclosure of my personal interest in the phenomenon of parental cancer, with which I am “intimately connected” (Moustakas, 1994, p. 59); my primary research question, which asked what the human experience is; and my chosen method for the collection of data (Creswell & Poth, 2018). Phenomenological researchers seek to describe “what” people experience and “how” they experience it, condensing data until reaching a final assertion of the experiences about a phenomenon shared by all people – “the essence of the lived experience” (Creswell & Poth, 2018, p. 122; Moustakas, 1994). However, in this study I set out to gain understanding as to “what” the study participants experienced, the realities and experiences specific to them, and what these experiences suggested in relation to the research questions I wanted to answer. Hence, thematic analysis was my chosen method of data analysis, influenced by grounded theory processes. Braun and Clarke (2006) asserted that thematic analysis permits a researcher to inductively analyse research data to identify patterns across the data, allowing themes of meaning to emerge. To this end, I incorporated a coding procedure, normally associated with grounded theory technique, in the data analysis procedure (Braun & Clarke, 2013; Saldaña, 2013), as I considered this the most appropriate procedure for achieving the aims of my study. It is important to note that, although grounded theory is generally concerned with the development of new theory about a phenomenon (Braun & Clarke, 2013), in this study the influence of grounded theory ideas is limited to the data analysis coding procedure. I have not sought to develop new theory in this study, as Saldaña asserted, “development of original theory is not always a necessary outcome for qualitative enquiry” (2013, p. 13). Rather, I have utilised the coding procedure to synthesise the research data into a thematic structure, in order to render and comprehend the unique lived experiences of the participants (Ozuem et al., 2022). Hence, the findings of my analysis are data directed, “grounded in data and the experience of the participants” (Sundler et al., 2019, p. 735).

4.3 Method

Data Collection

The data collection method chosen for this study was semi-structured interviews, which is the most widely used method in qualitative research (King & Horrocks, 2010). I chose this method because it aligned with my research paradigm and methodology, in that semi-structured interviews promote flexible and collaborative interactions between the participant and researcher, allowing participants to share their stories and experiences (Smith et al., 2009). The language used by research participants is understood as the way people report their subjective experiences and the meanings they create, and is the conduit by which researchers open and make sense of participants' internal world (Braun & Clarke, 2013).

Participants

Participants for the study were recruited from a private hospital cancer treatment centre located in Australia[1]. Criteria for participant inclusion in the study were:

- diagnosed with cancer 4-12 months prior to data collection;
- parenting one or more children aged 18 years or younger at the time of data collection; and
- competent in English

A total of eight participants were recruited, with one participant falling outside the inclusion criteria, relating to time elapsed since cancer diagnosis. Due to the protracted impact upon my participant recruitment caused by the COVID-19 pandemic, it was agreed, in consultation with my research supervisors, to accept this participant into the study. Braun and Clarke (2013) proposed that a moderate-sized study, utilising interviews for data collection and a thematic approach towards data analysis, should ideally have between six and 10 participants

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[1] The name and precise location of the hospital has been removed from this thesis and materials to maintain the confidentiality of participants.

to ensure sufficient data is collected. On this basis, a total of eight participants was considered appropriate for the study.

Prior to commencing data collection, additional demographic data was collected from the participants, to assist in establishing an understanding of their particular family structures, cancer diagnosis, and treatment trajectory. This data is summarised in Table 1.

Table 1

Demographics of Participants

Name*	Age, gender	Relationship status	Children – age, gender	Cancer diagnosis	Treatment
Erin	41, female	Married	male 10 female 8 male 6 female 3	Colorectal cancer	Surgery and chemotherapy
Denise	48, female	Married	male 23 female 20 male 15	Breast cancer	Surgery and chemotherapy
Rebecca	37, female	Married	male 10	Breast cancer	Surgery and chemotherapy
Lauryn	38, female	Married	female 13 female 11 female 7	Non-Hodgkin's lymphoma	Chemotherapy and immunotherapy
Ming	36, male	Married	male 8 female 3	Tonsil cancer	Surgeries, chemotherapy, radiotherapy and immunotherapy
Shivnath	44, male	Married	male 14	Bladder cancer	Chemotherapy and immunotherapy
Alex	40, male	Married	female 11 male 9	Bowel cancer	Surgery and chemotherapy
Lihwa	33, female	Married	female 5 female < 1	Breast cancer	Surgery and chemotherapy

*Pseudonyms have been used for all participant names

Materials

A participant recruitment poster, which included my name and contact details, was developed for advertising the study in the cancer treatment centre. A copy of this poster is available in Appendix A. A copy of the Participant Information Sheet provided to potential study participants is available in Appendix B. A copy of the Consent Form that study participants and I completed and signed, prior to commencement of data collection, is available in Appendix C. I also developed a Schedule of Interview Questions to act as prompts in guiding the semi-structured interview process, with the questions being informed by the research questions for the study. The opening interview question, 'What has been your experience of being diagnosed with cancer?', allowed participants to share their unique experience of having cancer, and the meaning they created from this experience. Secondary interview questions in the schedule related to participants' experiences within their family contexts and their encounters with family-focused care from oncology professionals and other support services. A copy of this schedule is available in Appendix D[2].

Procedure

Prior to commencement of participant recruitment, I delivered presentations to oncology nursing staff of the cancer treatment centre, to provide information about the project. The study was advertised in the cancer treatment centre through the use of the participant recruitment posters, and the nursing staff also *snowballed* information about the study through their ad-hoc interactions with cancer patients (Braun & Clarke, 2013). Upon being contacted by a potential participant, I confirmed that the person met the inclusion criteria and provided the person with a Participant Information Sheet. If the person wanted to participate in the study, a meeting was scheduled to take place in a private room on the cancer

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[2] Appendix B, C and D contain the original working title of the study, rather than the final title of this thesis.

treatment centre premises at a mutually agreed time, for a face-to-face semi-structured interview with me. Also, in order to comply with a condition of the ethics approval for the study, participants were provided with the Schedule of Interview Questions, for their information, at the time of scheduling a meeting (refer Section 4.4). Consent Forms were completed and signed by participants and me, prior to interviews commencing, with a copy being retained by each party.

Each of the eight participants took part in a single face-to-face semi-structured interview with me. The interviews were conducted in private space at the cancer treatment centre, audio-recorded with the permission of each participant, then transcribed verbatim. The average length of the interviews was 41 minutes, and the interview transcripts were deidentified, with pseudonyms used in place of the participants' names. Each participant was sent a copy of the transcript of their interview by post or email. I asked participants to review their transcript and if necessary, email me within 14 days to request any amendments or deletions they felt necessary. No such requests were received from participants within the allotted time frame; thus, I added each transcript to NVivo 12 Plus (NVivo) software in readiness for data analysis. Prior to commencing my analysis, I engaged in a period of familiarisation with the interview transcripts, reinforcing the time I had already devoted when listening intently to each audio recording during the transcription process. This entailed fully engaging with, and contemplating the participant data through reading and re-reading each transcript (Braun & Clarke, 2022) and recording my thoughts, ideas and reflections about each transcript as memorandums in NVivo (Byrne, 2022; Saldaña, 2013).

Data Analysis

Thematic analysis was my chosen method of data analysis for the study, as it is a widely used inductive technique in qualitative research, and an adaptable organised approach which assists researchers to develop concepts, meaning and perception (Ozuem et al., 2022). An inductive thematic analysis, as prescribed by Braun and Clarke (2006), involves the “bottom up” classification of repeated patterns, or themes of meaning, within a data set, to ensure the analysis is “data driven” (p. 83). Braun and Clarke (2006) also advocated that thematic analysis is an iterative undertaking, in that it involves “a constant moving back and forward” across the data set, through multiple stages of analysis (p. 86). A thematic analysis of data is a task that requires application of a multi-phased codifying procedure, and in this study I applied a three-phase coding procedure, commonly associated with grounded theory: open coding, axial coding, and selective coding, to arrive at the final themes and sub-themes detailed in the Findings section of this thesis (Braun & Clarke, 2006; Saldaña, 2013).

Open coding is an unrestricted initial approach towards the identification of interesting segments of data which may be pertinent, or of possible relevance, to addressing the research questions (Braun & Clarke, 2022; Saldaña, 2013). In applying open coding as a first-cycle coding approach to my dataset, I did not employ any strict prescriptive guidelines around number of codes, code labelling, or how data items were extracted; hence, multiple code labels were at times applied to the same data item, as Byrne (2022) asserted, “any data item can be coded in multiple ways and for multiple meanings” (p. 1402). Through this initial phase of analysis, I wanted to ensure coding provided the necessary depth to examine the patterns within the data and the range of participant experiences (Byrne, 2022). Each interview transcript was subjected to open coding, code labels were recorded in NVivo, and the relevant data segments were extracted and assigned to code labels.

In the axial coding phase, my key goal was to cultivate a notion of thematic structure from my open coding phase (Saldaña, 2013). This was achieved through the review, modification and enhancement of the initial codes into a smaller list of categories, underpinned by similarities in participants’ experiences and meanings, and the research questions I wanted to answer (Byrne, 2022; Saldaña, 2013). I conducted several iterations of this second-phase coding process, maintaining regular consultation and feedback sessions with my supervision team as to the progress of my analysis (Braun & Clarke, 2006). During this phase, some initial codes were re-labelled or amalgamated (Saldaña, 2013), and some codes were regarded as illustrative of a predominant aspect within the data to such an extent as to be elevated to a category (Byrne, 2022). Throughout this phase, the analytic structure was constantly updated within NVivo, including the allocation of relevant data extracts to codes and if applicable, categories.

The final phase of my coding method, selective coding, signified the synthesis of coding and categories into a formal thematic structure (Saldaña, 2013). The relationships between different categories were identified and those sharing an underlying and significant characteristic of the data were grouped within an all-encompassing theme. Moreover, categories which represented significant shared meanings and experiences amongst participants became sub-themes of the overarching theme (Braun & Clarke, 2006). In keeping with this final phase of my analytic endeavour, I consider the themes that emerged from the data represent “a coherent and lucid picture of the dataset” (Byrne, 2022, p. 1403) and hold bearing and significance to all participants in the study (Saldaña, 2013). As with the earlier coding phases, conduct of this final phase included regular discussion and feedback with my supervision team, and the final analytic structure was updated and maintained in NVivo, including supportive relevant extracts from interview transcripts. My analytic approach arrived at three main themes and eight sub-themes, and my analysis concluded with a written descriptive account of these themes and sub-themes (refer Section 5). The write-up includes supportive transcript extracts to provide an evidence base for my analysis.

4.4 Ethical Considerations

Prior to data collection, ethics approval 2020-072F was granted for my study by the University of Notre Dame Australia Human Research Ethics Committee. Additionally, ethics approval 1703 was granted by the St John of God Health Care Human Research Ethics Committee (SJOGHC HREC). In undertaking this study, I was also bound by the Code of Ethics of the Psychotherapy and Counselling Federation of Australia, of which I hold clinical membership. All representations, conditions, and requirements pertaining to the ethical conduct of the study, as detailed in the above-mentioned ethics approvals, have been followed in this study. Throughout the participant recruitment process, research participants were fully informed verbally and in writing about the purpose of the study, and their rights with regards to privacy and confidentiality. Written consent was obtained from all participants prior to data collection. In accordance with a specific condition requested by SJOGHC HREC, a Schedule of Interview Questions was provided to participants prior to interview meetings, in view of the sensitive subject matter being investigated. To ensure anonymity for participants, audio recordings of interviews were deleted following transcription and member checking, and pseudonyms have been used in place of participant real names in the transcripts and this thesis. All raw data records, such as interview transcripts, demographic data and research materials, will be stored in accordance with the University of Notre Dame Australia Policy and Procedure: Research Data Management.

4.5 Trustworthiness

The philosophies which underpin qualitative research, commonly put qualitative enquiry at odds with the widely accepted criteria for evaluating the validity of quantitative studies (Braun & Clarke, 2013). The knowledge gained from qualitative enquiry is not generally universally applicable as principles or rules, nor is it based on the statistical analysis of data in the form of numbers; rather, it is representative of deep and contextually located understanding about a phenomenon (Braun & Clarke, 2013; McChesney & Aldridge, 2019). Indeed, qualitative researchers do not “aim for replication”, either as an underpinning law, or as the measure that establishes research quality (Braun & Clarke, 2013, p. 20). Whilst there are no definitive benchmarks for evaluating the merits of qualitative studies, a number of researchers have developed various standards and procedures suitable for the evaluation of trustworthiness in qualitative investigations (Braun & Clarke, 2013; Nowell et al., 2017; Sundler et al., 2019). Fundamentally, for studies to be considered trustworthy, qualitative researchers “need to be clear about what they are doing, why they are doing it, and include a clear description of analysis methods” (Nowell et al., 2017, pp. 1-2). Sundler et al. (2019) referred to the potential for “phenomenological validity” through adherence to reflexivity, credibility and transferability (p. 737). I will refer to these strategies further in this section.

Reflexivity refers to my subjective understanding of my role as researcher – how my experiences, perspectives, assumptions, interest in a phenomenon, and research questions, can shape and influence the course of this study (Braun & Clarke, 2013; Creswell, 2014). My capacity to put aside, or “bracket” personal feelings, assumptions and preconceptions, so as not to allow my own knowledges and constructs to intrude upon the process of data collection and analysis, has been “an iterative and reflexive journey” (Ahern, 1999, p. 408). Reflexivity is not about issues of bias, rather it refers to my capacity for reflective practice throughout the research process, in order to enhance my contribution to the process (McLeod, 2015). Ahern asserts that our capacity for bracketing is an operation of our capacity for reflexive activity, “because it is not possible for researchers to set aside things about which they are not aware” (Ahern, 1999, p. 408). For my reflexive practice in this study, I was acutely aware of the sensitivity associated with the subject matter, my personal experience of the phenomenon, and how this experience informed my motivation and impetus towards the study. For these reasons, I focused particular attention on maintaining awareness around my personal responses, reactions, and processes over the course of the interview activity. I attended to this reflexive approach by keeping a journal for my reflections on the participant stories, my personal responses and reactions, and how I conducted the interviews (Hadi & José Closs, 2016). I complimented this attitude towards personal reflection through my full and consistent engagement in external supervision and peer debriefing during the interview process; moreover, I extended my reflective activity to encompass the transcription and analysis phases of the study (Hadi & José Closs, 2016). Further, I have been transparent in this thesis as to my personal background and experience of the phenomenon in question. Adherence to reflexivity is a key tenet of the qualitative principles underpinning this study, to ensure my data analysis allows participant experiences to be fully heard, rather than my own assumptions, personal beliefs and understandings (Sundler et al., 2019). I assert that my reflexive practice and attitude established and supported the ethical safety of the participants, and has enriched my contribution to this research endeavour, promoting trustworthiness in the research project;

Sundler et al. (2019) asserted that to meet the test of “credibility” in qualitative research “the procedures and methods need to be presented as thoroughly and transparently as possible” (p. 737). I have striven to provide comprehensible information around my methodological choices and deliberations in the development of the study design. Further, my commitment to thoroughness and transparency has also applied to my descriptions around how the data analysis was conducted and the findings presented, allowing a reader to understand the reasoning behind the themes and sub-themes reported in the findings (Hadi & José Closs, 2016). Moreover, descriptions of themes and sub-themes are supported by quotes from the dataset to ensure consistency (Sundler et al., 2019). Additionally, the unique and “thick descriptions” provided by the participants, the member checking process I followed, allowing all participants to review the transcripts and make any changes or deletions they wanted, and the extensive involvement of my research supervisors in data analysis and theme development, indicates the technique known as triangulation, further enhancing credibility (Nowell et al., 2017, p. 3).

Finally, Sundler et al. (2019) considered the test of a study's transferability from a qualitative perspective as being "a measure of whether the findings are sound and if the study adds new knowledge to what is already known" (p. 737), offering findings that may be relevant in other distinctive or expansive contexts, other than the original setting. Whilst my intention was never to produce generalisable findings of a statistical nature, as in quantitative research (Braun & Clarke, 2013), I assert that the findings of this study, the opportunities for further investigations that have emerged, and the implications for family-focused oncological care and support for parents diagnosed with cancer, are indicative of a study that meets the above transferability test. At a fundamental level, I do not claim to have produced a data analysis that describes an objective or "absolute" truth, as such a claim would not align with my interpretive/constructivist paradigm, or my chosen methodology; rather, I have produced a subjective, truthful and trustworthy analysis of rich and unique participant experiences, "plausible, coherent and grounded in the data" (Braun & Clarke, 2013, p. 21).

5 Findings

In this section, the central findings that emerged from the analysis of the interview dataset are presented. The coding procedure applied to the data analysis identified three major themes that emerged from the participants' descriptions of their experiences. The three key themes identified were: Hearing the Words "You Have Cancer", Bringing Cancer Home to the Family, and Playing the Hand You Are Dealt. The three themes are further supported by eight sub-themes, as detailed in Table 2. The three themes are described in detail, supported by participant quotes from the interview data. A brief summary of the key findings to emerge is provided at the end of this section.

Table 2

Table of Themes

Theme 1 **Hearing the Words “You Have Cancer”**	
Sub-theme	**Participant Statement**
Becoming a Cancer Patient	“*I was very mentally shaken. I couldn’t really speak and I got this very hot flush sort of feeling.”*
Wading in the Unknown	*“All I could see was all the things that weren’t gonna happen.”*
Theme 2 **Bringing Cancer Home to the Family**	
Sharing Openly	*“We had to sort of hide everything. Everything was hush, hush and whispers.”*
Changes and Challenges	*“My son’s big thing right at the start, ‘Will you look different?’”*
Dealing With It	“*We do a good job of providing suspension for the kids, we try to minimise the impact of news.”*
Theme 3 **Playing the Hand You Are Dealt**	
Acceptance	“*It’s definitely part of our life … I have good days and bad days, mostly good.”*
Resilience	“*Somehow, I have confidence in myself, I’m going to defeat this disease and I’m going to survive”*
Identity	*“work is very much part of my identity and if that’s completely gone, the other part of me is being [a] mum.”*

5.1 Theme 1: Hearing the Words "You Have Cancer"

This theme captures the participants' descriptions of their experiences and perspectives in relation to being diagnosed with cancer. The participants described their experiences around the immediate medical necessity of becoming a cancer patient, whilst confronting the impact their diagnosis could have on them and their families. The two sub-themes describe this juxtaposition between the participants' engagement with the practicality of medical science and treatment, and the emotional anguish and uncertainty thrust upon them.

Becoming a Cancer Patient

In responding to the opening interview question, the participants described their experiences of the medical process involved in their cancer diagnoses, as well as their immediate reactions upon learning they had cancer. The participants expanded upon their medical experiences, offering ideas around what would have been helpful to them in the beginning of their cancer journeys. Further, the participants shared their experiences of guidance, or lack of guidance, from the health care professionals they encountered during this time, particularly in relation to what effects the diagnosis may have upon their families, and how this could have been managed.

At the time of being interviewed, the participants were generally highly complementary of the medical care and support they had received from the health care professionals involved in their cancer diagnosis and treatment. Nevertheless, some participants recounted difficult experiences around the process of learning they had cancer, including interactions with health care professionals they found unsettling and unexpected. Such experiences were distressful for the participants, and impacted their confidence, trust and hope. Erin described a *"bizarre"* encounter with an emergency department doctor when being delivered distressing news about her medical condition. She had been taken to hospital by ambulance, experiencing strong pain she believed was a reaction to a recent appendectomy. Erin had not received any indication she may have cancer prior to admission to the hospital's emergency department:

> *The doctor had probably seen what the scan had shown and was wondering why I hadn't done anything earlier about it … so for he to come back in later in that evening and just say … "Well, I've seen your scan and it looks like you've got a mass and there's masses everywhere. I realise this is a shock but then I don't like giving you this news either."*

Shivnath was accompanied by his wife and 14-year-old son when he was told he had stage 4 cancer by his doctor. Shivnath described his doctor crying when giving him this news and the impact this had on him and his family:

> *It was so raw. If you're conveying to someone, you're stage 4 cancer, how would you convey, how would you prepare yourself? If the doctor is crying in front of me, what confidence will the patient gain? It has some impact on the patient or the immediate family members.*

Shivnath offered poignant insight into the distress experienced by his doctor in delivering the diagnosis: *"when you're having dialogue with a patient in such critical scenarios, I guess, even doctors need counselling."*

Alex shared a similar unnerving experience early in his cancer journey, which impacted his trust and solace in the medical care and treatment he had received. Alex described receiving a response from a nurse which contradicted what he had been told by his oncologist:

> *Those kinds of things don't help, because they shake you. You get this concept of the structure of where you are, what the future is and get your emotions and everything built around that, and you go hang on, how strong is this structure? Am I kidding myself and I'm doomed?*

All of the participants shared openly about their immediate reactions upon hearing the words "You have cancer." The predominant reactions described by the participants were shock, fear, and other complex feelings, depending on contextual factors in participants' lives, and the staging of the disease. Ming and Alex spoke vividly of their somatic reactions to the news. Ming received a telephone call from his doctor and was given the news, whilst in the process of helping his then 1-year-old daughter to bed: *"I just can't function. My mind can't think of anything and it seems like my spirit is out of my body. I go to the ceiling and look at myself."* Alex described the physical *"shutdown"* he experienced upon hearing the news: *"I was very mentally shaken. I couldn't really speak and I got this very hot flush sort of feeling. I was undoing my shirt and I thought I was gonna be sick. I couldn't really think about anything."* Alex went on to pose a succinct recognition of the power inherent in the word *"cancer"*: *"Saying cancer's like saying bomb in an airport isn't it, it's got more gravity potentially than any other word in the English language ... the impact it has, just to say the word."* Shivnath described his shock upon learning of his diagnosis, however being very aware of his wife and son by his side: *"It was ... very shocking for me when I heard it first, but ... I had my wife and my child by my side so, I had to be like very strong."*

The particular circumstances some participants were already facing in their lives also had a bearing on their reactions to being diagnosed with cancer. Lauryn described how she had been feeling unwell, whilst coming to grips with the recently diagnosed terminal recurrence of her husband's cancer. Lauryn shared her conflicting emotions upon hearing the news of her own diagnosis:

> *I was relieved to have an answer to why I had been feeling ill for so long, that there was something going on that could be cured potentially ... but it's just disbelief, thinking how can this be both of us.*

Lihwa also spoke of contradicting and complex emotions in response to her diagnosis of breast cancer, having received the news just prior to the end of her second pregnancy: *"I was supposed to be really happy, but my feelings were ... very complicated. I was not only upset. Upset is not enough for me to describe my feelings."* Lihwa's emotional reaction was further complicated when told she would need to undertake a mastectomy to remove her breast, and would not be able to breast feed her newborn child due to the effects of chemotherapy: *"If you breast feed with your child, you have the bond, you know what I mean? But when you're not breast feeding, you've sort of lost the bond."*

During the interviews, many of the participants offered views and ideas around what would have been helpful to them in the early stages of their cancer diagnosis and treatment. Specifically, some participants expressed the need for emotional and psychological support to be made available as a component of the initial medical intervention, and as an ongoing resource. Whilst the participants acknowledged the availability of information if requested, such as written information (in the form of pamphlets) about various external cancer-related service organisations and practitioners, some participants felt the emotional distress and overwhelm experienced in these early stages were too impactful for them to comprehend and access such information.

The participants spoke of how having dedicated support instigated upon becoming cancer patients, would have been helpful at a time when they were still confronting the impact of being diagnosed with cancer. Rebecca expressed strong views around the need for early emotional support and education: *"I feel like there's that gap of education at the beginning ... almost a counselling session, right at the beginning. It's at the start you need it, cos you don't know what's going on ... you're just so overwhelmed."* Erin suggested having a person assigned to cancer patients, with the role of coordinating the patient's access to support: *"Almost like a case worker or social worker who helps you link into all that sort of* *stuff. At the beginning, as opposed to when the wheels fall off later down the track."* Shivnath expressed that having access to counselling in the first days after receiving his cancer diagnosis would have been valuable, particularly for his wife:

> *Because that is the crucial period, the initial period. When you are absolutely in shock. That's where this counselling would definitely help. But my wife's condition was very bad, for the first two days she was not in her senses … and counselling would have definitely helped.*

Some participants suggested the availability of peer-based group programs, which allowed them to share their experiences with other cancer patients in similar circumstances, would have been beneficial to them. Erin also recognised how her particular circumstances, being a mother to four young children, may have allowed her to help others:

> *Another thing that would have been really good for me was if I had contact with other people in the same position. I felt like I can actually kind of help somebody else … because I can understand about being my age with what is going on.*

During the interviews, the participants were asked if the oncology professionals involved in their care and treatment had provided any initial guidance, or raised awareness for the participant, around the common impacts on families of a parental cancer diagnosis. Participant responses were mixed, yet generally any discussions with oncology professionals around family were centred on questions about the family structure and general family wellbeing. Specific guidance and awareness raising did not generally occur, although some participants acknowledged they did not seek such guidance themselves or did not pursue discussions when the topic of family was raised. Denise recognised that she did not engage in discussions when questions as to how the family was coping were posed: *"They've all asked how many children I have, how old are they, how have they been with this. Maybe it just gets dropped because I've said pretty much no, everything's okay."* Denise also spoke of the breast care nurse as a health care professional involved in her care who had offered thoughtful suggestions around the impact on Denise's family, and also acknowledged that support and guidance was always available if needed: *"She's probably been the one who's really been putting things out there and asking me questions and making me think about things. I mean, I've always known I can ask if I need more help or support or information."*

Lauryn said she was made aware of various resources by staff of the Cancer Centre, but had not pursued these resources. However, Lauryn did describe an unhelpful interaction with a practitioner in the hospital around Lauryn telling her children about her diagnosis:

> *She was very opinionated about me telling the children but I wasn't officially diagnosed. I didn't want to tell them at that point, because I had all these other things going on with my husband and I just felt it was just too much for me to even get my head around before I wanted to go there.*

Erin described the oncology professionals involved in her care and treatment as being focused on the medical approach, without an appreciation for the impact her treatment could have upon her role as a mother. Erin recounted a particular interaction at the beginning of her treatment, when enquiring around neuropathic side effects:

> *The comment back was ... "Oh well, you just can't change nappies anymore." It sounds a bit trivial but that's a big deal for me if I can't change my kid's nappy when I'm at home. That is a big deal for me.*

Erin went on to share that she had taken it upon herself to source consultations with a palliative care doctor, for more holistic support around pain management, as the normal pain medication she had been prescribed was impacting upon her role as a mother. Erin expressed that it would have been helpful for this to be considered at the outset of her diagnosis, but she felt uncertain about raising it with her treating medical team: *"I was unsure about asking about palliative care cos I felt I didn't want my medical team to think that was me, you know,* *throwing in the towel."* For Ming, the question around professional guidance allowed him to look back at the experience within his own family, and he offered strong views around the opportunity oncology professionals have to offer early guidance and support to cancer patients and their families:

> *Maybe they can do a bit more about the changing roles in the family and what may happen in a young family, for the kids ... the experience that you may go through ... sharing about the experience of other families ... so we have more expectation about what's going to change. Maybe the medical staff can share more, because they are the first ones the family will see, they're the front line.*

This sub-theme captures the participants' descriptions of their immediate experiences of learning they have cancer and the medical necessity of becoming a cancer patient. During data collection, the participants also described their personal experiences, in this early period of cancer diagnosis, in confronting what their diagnosis might mean for them and their families. Descriptions of these experiences are captured in the following sub-theme.

Wading in the Unknown

This sub-theme denotes the participants' emotional and cognitive experiences in the immediate period of receiving their cancer diagnoses and commencing treatment planning and implementation. The participants expressed a range of emotions, cognitions and insights as they waited for the medical wheels to turn, and they confronted the palpable threat their diagnosis posed to their life and future. The participants also shared their thought processes as they struggled to find grounding and make sense of the situation they faced.

Some participants described their difficulties in navigating the early diagnosis period, aware they have cancer and having to wait for such things as further medical appointments, test results, treatment plans, surgeries, and the commencement of intensive treatments. Rebecca and her family had moved from interstate six weeks prior to her diagnosis, and she had recently started a new job. Rebecca likened this period to being *"in limbo"* and described her struggles:

> *So that waiting time, where you're sort of just in limbo waiting for dates and things, it's sort of like play on, just do your job, go to work, nothing's wrong, but it's not, you're falling apart. I'm not my confident, I'm not my bubbly … because right now, the worst thing possible is happening on the sidelines.*

The participants shared their experiences and insights around the life-threatening nature of cancer, and confronting their mortality. For some participants, the advanced staging of their disease made the threat immediately tangible. The participants described a range of emotions and cognitions in response to the uncertainty they faced in the early days of diagnosis and treatment. Shivnath described becoming instantly aware of what his diagnosis of stage 4 cancer meant, and wanting to know how long he had left to live: *"Because stage 4 is the final stage, like no going back. So, how long can I live, how much life is left in me … and whether treatment is going to help me or it's like I'm … hopeless."* Similarly, Erin expressed how the spread of her disease meant her future was no longer what she had expected it to be:

> *All I could see was all the things that weren't gonna happen. It's probably the biggest thing. Changing the way you just plan your marriage about, will we sell this place and will we move here … suddenly wasn't relevant anymore.*

Lihwa spoke of being very emotional and sleep deprived as she prepared for the birth of her second child, whilst contemplating the cancer diagnosis she had received a few days prior: *"I thought, this is the same as other cancers, like I probably cannot live for, maybe can only live for, 3 years, 5 years. Then I won't be able to see my baby grow up."* Relatedly, Alex contemplated recording his life story and writing letters of goodbye for his children, in whatever amount of time he had left. Alex became emotional during the interview as he recounted how difficult it was for him to write to his children: *"The letters to the kids, that was the bit that … I could barely consider it and every time I thought about it, it was like, what can I possibly write, how do I write it?"* Denise described how she had protected herself from the seriousness of her condition through the early stages of diagnosis and surgery by focusing on the medical procedure, and how this changed on her first day of chemotherapy treatment:

> *The day we drove in for the actual first chemo session … it just hit me. It just became very real. That it really is cancer. I think I just couldn't accept it was such a potentially life-threatening thing … that could change the dynamics of like our whole family, if it didn't go well.*

The participants described their thought processes during the early days of their cancer journeys, as they contemplated and made sense of their diagnoses and what it could mean for them and their families. For some participants, making meaning from their situation was a focus of their thinking. Ming questioned the meaning he had found in his life through wealth accumulation and success, having been diagnosed with cancer:

> *I've still got two houses, I've got cash in my bank account, I've got a lot of rewards at work. None of that can actually negotiate with my situation. It seems like what I did before is just all meaningless.*

Alex described his contemplations around how his possible death from cancer may shape the development and characteristics of his children: *"If they didn't have a dad … maybe that gives them strength, because they have to cope with a more difficult upbringing. Maybe they'd come on more autonomous."*

Some participants also described the immediate importance for them to focus on what steps they could take to mitigate the practical and emotional distress their family would suffer if they were to die or be incapacitated by their illness. Alex spoke of his thoughts around, should he die, making the process following his death as *"administratively"* simple as possible for his wife and family:

> *If I was gone, they'd be sort of incapacitated temporarily, particularly with the mental state they'd be in. So, I thought, to the extent I can get all my passwords, get all my member numbers for life insurance and photos, records, this kind of thing ... the easier it would be for them to do the task that they have to do.*

Shivnath also spoke of wanting to use whatever time he had left to ensure his family's continued financial wellbeing was in place, and expressed what any parent with cancer might be concerned about: *"Obviously, one major worry, that any patient would have, a cancer patient ... what about my family after me?"* Conversely, Erin considered a longer-term focus on what she can achieve, particularly for her children, in the time granted by her terminal prognosis:

> *I'm a big planner, 5-year plan, 10-year plan, school for kids, all that kind of stuff. So it's trying to get my head around how do I operate in 3 to 5 years and get all the things I want done, then making sure that all my plans for the future, for the kids, still happen.*

The findings described in this first emerging theme from the data analysis, provide an encapsulation of the challenges the participants experienced in the immediate period of learning they have cancer. The participants described their cognitive and emotional responses to both their essential engagement with the medical community as a cancer patient, and the implications of their illness, both personally and for their families. The participants' experiences of living with their diagnoses and treatments, within their family contexts, are described in the second theme to emerge from the data analysis.

5.2 Theme 2: Bringing Cancer Home to the Family

The participants' descriptions of their experiences within the context of immediate and extended family are captured in this second theme. During the interviews, the participants described their approaches towards sharing their diagnosis with family members, particularly their children, and the communication challenges they have encountered within the family in response to their diagnoses and treatment to date. The participants also spoke about their experiences of the various impacts their diagnosis and treatment have had upon the family, and what changes they have noticed within the family and with individual family members. Further, the participants described the steps and strategies taken within the family to mitigate these impacts and help family members cope. A descriptive account of these experiences is provided in the three sub-themes below.

Sharing Openly

All of the participants spoke about the approach they took towards communicating about their diagnoses and treatments with other family members, particularly their children. Some participants described wanting to be open with their children about the illness and how it might impact the participant and the family. Conversely, other participants spoke of not knowing how to tell their children, and uncertainty around how much information should be shared with their children. In such circumstances, the participants expressed concerns around how not sharing openly and fully with their children, out of wanting to protect or shield them, might conversely create worry and emotional difficulties for children. The participants also described their uncertainty as to the emotional impact the news of their diagnoses and the ongoing effects of their illness might have had on their children, and how emotions could be expressed openly within the family. The availability of resources to help parents talk with their children and promote dialogue about the illness and treatment side effects was described as an important issue by some participants. The participant descriptions of their experiences referred to the developmental age of children, stage of the illness, and other family circumstances, as factors involved in how communication about the parent's cancer was approached within the family.

Being open with children and other family members about the diagnosis, treatment, and wellbeing was important to some participants. Lihwa described her approach towards telling her 5-year-old daughter about her illness and need for a mastectomy:

> *I think that's very important, to tell your child what's happening and then just use the words that they understand. I told her everything in advance. Even though they don't really understand, you still need to tell them. Otherwise, you will never know how this is gonna affect the children's behaviour.*

Alex described his difficulties when contemplating how to tell his children about his diagnosis, being unsure around using the word *"cancer"* and what it would mean for his children. Alex went on to recount how his wife took direction of their open approach towards communicating with their children:

> *For it to be said out loud and daddy has it ... that means to them, daddy's gonna die. My wife said, "You're gonna be going through chemo, if we don't describe what's gonna happen, they're gonna be hearing it from friends and they're gonna be deciding this stuff by themselves".*

Shivnath described the extent of open communication practiced with his 14-year-old son, who had been present when Shivnath learnt of his stage 4 cancer diagnosis:

> *Since the beginning, we never hide anything ... whatever happens ... my son was always across what we are doing, what our plans are. He understands what is going to happen and what he needs to do, what he needs as well, how he needs to support mum and dad, and what kind of support he will get from mum and dad.*

Some participants felt it was important to be open with other family members as to how they are feeling, both physically and emotionally, so other family members are informed and aware. Ming described how his openness with other family members about how he is feeling and coping with his illness, rather than keeping it to himself, helped to ease uncertainty and worry for family members:

> *They will think too far, if I'm hiding too much. Then they will start to imagine a lot of things, which is not necessary. The more information they have, the more secure feeling inside. The more guidelines for them, they feel so much better.*

In contrast to the above experiences and approaches towards communication, some participants described not knowing whether they should tell their children of the cancer diagnosis at all, or how or what to tell their children about being diagnosed with cancer, due to concern for how it might affect their children; and self-doubt around their capacity to communicate the news appropriately and effectively. Erin, faced with a terminal diagnosis and parenting four children aged 10 years or younger, described her predicament in wanting to tell her children the extent of her illness, and not knowing how to do it without causing her children ongoing distress:

> *Being at different ages they're going to need different things and I wish that there was something that would tell me what to tell them, when to tell them and how much to tell them. I want them to know but I'm very conscious of ... I'll mess it up. I don't want to say the wrong thing around death, when the kids aren't ready for it and have them stressing for the next 3 or 4 years.*

Erin went on to describe her efforts to locate resources that could help her talk with the children about her illness, as well as support the children directly. Erin spoke of finding little in the way of resources appropriate for the ages of her own children, saying that the resources she found seemed directed towards children of adolescent age:

> *I guess it's unfortunate and unusual for a young person with young kids to get diagnosed with cancer. It's just that awareness that it's not as common, you're more likely to be going through this when you're older and you've got older kids.*

Erin continued to discuss the idea of new resources to help with the communication challenges she had experienced with her children, including possible counselling interventions at a family level:

> *Resources as in things that are just for the kids, or things that will help me, tell me what to do. Or even situations where I get to … work with the counsellor with the kids in the room and help facilitate conversation.*

Lauryn and her husband had already chosen not to tell their children about the terminal recurrence of his cancer, and this approach was again taken initially when she received her diagnosis, out of concern for how the children would take it. Lauryn described how challenging this initial period was within the family, how she was aware of the possible paradoxical consequences of not informing the children, and her questioning of what constitutes protection of children:

> *We had to sort of hide everything. Everything was hush, hush and whispers. But I'm very aware that when children hear whispers and they're not quite aware of what's goin on it can also make them more scared, but I feel like as adults we have to protect them in that sense as well. I don't know if not telling them was protecting them. It's a debate in my head constantly.*

Some participants described their experiences around the expression of emotions within the family, how such expressions were encouraged or suppressed by family members. Ming offered an emotional description of the importance in which the open expression of feelings is viewed in his family, and how it helps him and his family cope with his illness. Ming provided an example of this in his interactions with his oldest son:

> *Open expression actually gives you more release and more knowledge about yourself, and when you talk about your emotions to others, we can share our experience, and this actually helps. When I share my suffering with him, sometimes he will cry. We face the suffering; we don't run away. I think this is a good lesson for him.*

Whilst a number of participants spoke of their approach towards open communication within the family, some participants also described their uncertainties when considering the possible emotional reactions family members were suppressing, particularly children, and how to talk about these concerns. Rebecca described how the message she and her husband communicated to her son was *"always that I'm just gonna be okay"*, and her reluctance to talk with her son around possible underlying feelings: *"I don't know how to talk to him and go deep, unless he goes deep with me. I'm sort of reluctant to touch the surface."* Alex described how understanding and accepting his children were of the news of his cancer when it was delivered to them by his wife, *"with very limited displays of grief or anxiety"*; however, being unaware of how his children may be coping emotionally with the news: *"We're not sure how much underlying anxiety and problems it is causing them. It doesn't show ... but of course, you only see the surface of the ocean, don't you."*

This sub-theme provides a descriptive summary of the participant's approaches towards talking about their cancer diagnosis within their family contexts, and the challenges such communication presented to them and their families. The following sub-theme addresses the participants' experiences around the impacts of their initial diagnosis and ongoing treatment upon their families, and what changes they have witnessed within the family and with individual family members.

Changes and Challenges

This sub-theme encompasses the participants' experiences of change and effects, in and on the family, and individual family members, as a consequence of the participants' cancer diagnoses, treatment and wellbeing. During the interviews, the participants shared their experiences around the physical impacts and changes within the family. The participants described their own physical changes in relation to their cancer treatment and side-effects, and other physical impacts they have noticed, such as changed behaviours on the part of family members, particularly children. The participants described changes in their families as family members assumed new roles and responsibilities, in response to the participants' incapacitation or unavailability due to their illness, including such impediments as treatment commitments and side-effects, and hospital admissions. The participants also shared their experiences of changes and challenges in relationships within the family, particularly relationships with partners and extended family members, in response to their illness.

The participants spoke about the physical changes they experienced as a consequence of their treatment regimens and side effects, and the affect these changes had upon themselves and other family members, especially children. For many participants, the loss of hair due to chemotherapy treatment was described as visible proof of their illness. Denise described collecting a wig from a service prior to starting chemotherapy treatment, in anticipation of losing her hair, as an *"in-your-face"* acknowledgement of her illness: *"I think just going there for me … and the kids … that's acknowledgement that things will change, even if it's just physical at that point. Like 'mum's actually sick.' You can't ignore that."* Lihwa had told her 5-year-old daughter about the physical changes she would go through due to her treatment, including the initial loss of her breast, and the loss of her hair due to the medicine she would be taking. Lihwa described her daughter's reaction when first seeing her mother without hair: *"When she realised, I have no hair, she looked at me smiling but with a very awkward smile. Like she wants to smile but she doesn't really know how to express her feelings."* Rebecca described her 10-year-old son's *"biggest fear"* as she commenced chemotherapy treatment: *"My son's big thing right at the start, 'Will you look different?', his* *question was 'Will you look different?'"* Erin had initially believed her treatment would be for 6 months, and had promoted with her children that after she finished treatment, she would be well and the family could enjoy Christmas together. Unfortunately, medical scanning determined that her treatment would be ongoing. Erin recalled vividly her 10-year-old son learning of this when, having returned from a stay with his grandmother, he saw the physical evidence that her treatment was continuing:

> *I had treatment and I still had the bag attached. I just remember my eldest, who's 10, he came in and just stopped at the door and said, 'I thought you said you've stopped', and at that point I realised I hadn't stopped to explain to them that no ... this is ... gonna be ongoing.*

Some participants described changes in the day-to-day routine of family life, due to the demands of their cancer treatments, the impact of side effects, and unexpected hospital admissions. Changes included cancelled family holidays, and not being able to take part or assist in normal family activities, such as junior sport or assistance with homework. Ming spoke about his children having to adjust to his unavailability:

> *When I'm in treatment, they've learned to be more patient. At the same time, they've started to learn to maybe look for others ... while I can't spend time with them. They're learning so much quicker, because they're forced to learn.*

Alex's diagnosis and treatment demands meant that a planned family camping holiday with other families associated with their children's school could not proceed. Alex described the affect this had for his children:

> *They're very sad about not being able to go on a holiday with their friends. I can imagine how valuable that is to them. It's been very difficult to have the tears ... and*

> *they get it, but it's very hard for them to accept and I think there's sadness around that.*

Erin described impacts upon her two youngest children, stemming from such physical changes as her emergency hospitalisation, and new home environments. Erin described her then 5-year-old son's reaction following her being rushed to hospital in an ambulance:

> *He probably reacted the worse ... I think he was quite frightened when I ended up having to go in an ambulance. I would Facetime them from hospital and he wouldn't come onto the screen and when I got home ... a week before he came anywhere near me, he would just stand in the kitchen and watch me, but very unsure about what was happening.*

Further, Erin recounted how the changed physical home environment, following her diagnosis, affected how her 3-year-old daughter interacted with visitors. Erin said the household was very busy, with many visitors coming and going in support of Erin and the family: *"Often, you'd hear her, she'd answer the door and say 'Hello, mum's sick' to whoever's at the door. But that's all she kind of knows."*

Some participants described behavioural changes they have noticed in their children, since receiving their cancer diagnoses and commencing treatment. For Rebecca and Lihwa, changes in their children's bedtime and sleeping habits were noticeable. Rebecca described a change in her 10-year-old son's usual bedtime routine, wanting to sleep in his parents' bed: *"He's not going straight to bed on his own ... just wants to be near me until he knows I'm asleep and safe or…I don't know what it is."* Similarly, Lihwa spoke about her 5-year-old daughter's behaviour change when being put to bed, following Lihwa's two absences due to hospital admissions. Lihwa said her daughter previously would settle into sleep very quickly, and described how this changed, and what sense she made of this change:

> *When I tried to put her to sleep, she always held my hand, she didn't want to go to sleep … just kept staring at me. She might think that I probably will leave her anytime and she just feels unsafe.*

Denise and Shivnath described contrasting changes in the behaviour of their adolescent children. Denise said her 15-year-old son used humour in the early stages of her diagnosis and treatment, saying such things as *"I'm gonna play drums on your head."* However, as her treatment progressed, she noticed a change in his behaviour: *"But now that it's happened, he won't touch my head. I'm not sure if he's hiding a lot of his feelings. He does seem to be getting a bit more frustrated lately."* On the other hand, Shivnath offered what changes he has noticed in his 14-year-old son, describing his son's growth and maturity since learning of his father's cancer diagnosis at the same time as his father. Shivnath went on to detail his son's commitment towards Shivnath's adherence to healthy behaviours, describing his son as his *"strongest support system in the house"*:

> *The way I used to see him and the way I'm seeing him now. He is very, very matured and he's thinking about what is going to happen, how long will my dad be around me, and what will be my life after that. He's helping me, he's encouraging me to do exercise, to eat well … if I had been in his position, I don't know how I would have reacted.*

Shivnath's wife, who joined her husband during the course of the interview, spoke of their son's initial emotional *"meltdowns"* in the early days of learning about Shivnath's diagnosis. Shivnath's wife said that following these emotional early days, their son's positivity had grown, and described how their son's commitment to his father's health regimen has extended to his engagement with medical test results: *"He loves to understand the human biology notes, whenever he gets the reports, he's going through it, looking into it. He has his* *own analysis before we go and meet the doctor."*

During the interviews, all of the participants shared their experiences around the impacts upon roles and responsibilities within their families. Participants described changes which had occurred in several aspects of family life, such as the day-to-day *"tasks of living"* all families experience; duties normally the sole responsibility of participants; and responsibilities previously shared with partners. Some of the participants made reference to particular factors associated with these changes, such as cultural norms, the staging of the illness, and financial implications. Many participants recognised how the repercussions of their illness had placed short-term and long-term pressures on their partners. Ming spoke of the change in roles and responsibilities for his wife, due to his ongoing incapacitation in response to intensive treatment, and the pressure such changes have placed upon her:

> *My wife used to be really reliant on me, she didn't have to take a lot of responsibility at home. But because of my situation, she needed to do a lot more than before ... she is more stressed, because she has to work as well, she's taken up a lot of responsibility on her shoulders.*

Some participants spoke of the financial implications for families when a parent is diagnosed with cancer, and the pressure this might place on partners and family members. Erin spoke about the financial responsibilities and burden associated with having a young family, and how she and her husband had shared this responsibility by both working. Erin described how her terminal cancer diagnosis and ongoing treatment meant she could no longer work, placing additional pressure on her husband, and impacting plans they had for their children:

> *Having a sole income to send four kids to school and us thinking we can't send them to this school anymore ... and the pressures, knowing that'll only be on him going forward, because we don't have our flexibility of two of us working.*

Shivnath referenced the cultural norm in his country of origin, in relation to the financial management of the family, and significant decisions regarding children's education, whereby *"the male would take care of all these things."* Shivnath described how his stage 4 cancer diagnosis necessitated a more mutual approach to such matters with his wife, in anticipation of her assuming sole responsibility:

> *Okay, what is happening, what we have and how you can learn to live your life after me. How you are going to survive. It's more collaborative, more hand holding is happening, we are sharing a lot of information, we are kind of doing it together.*

Some participants shared examples where other family members had *"stepped up to the mark"* by taking on roles and responsibilities within the family that would normally be attended to by the participant. For example, Lihwa described how her mother-in-law and father-in-law, who both live with Lihwa and her husband, had relieved her of parenting responsibilities since the commencement of treatment, particularly during the early surgical procedures, so Lihwa could rest and *"get ready for the second breast surgery."* Similarly, Denise described how her 20-year-old daughter had assumed a *"mothering role"* for Denise's 15-year-old son since the cancer diagnosis:

> *This really made her grow up a bit I think, probably in a role she shouldn't have to do obviously. But she's done it off her own back and been happy to do that, and we make sure we recognise that regularly.*

In the course of the interviews, the participants shared their experiences around changes and challenges in family relationships in response to their cancer diagnoses and treatment. These experiences were often in relation to their partners; although, experiences concerning children and extended family members were also recounted. For some participants, relationships were enhanced and mutually supportive, providing encouragement and meaning for participants. For others, the diagnosis evoked relationship experiences characterised by uncertainty, dissonance, and disappointment.

Alex spoke of his *"hyper"* and *"enthusiastic"* approach to maintaining a positive persona in the face of his diagnosis and treatment, and how challenging this had been at times for his wife *"to keep up."* Alex recognised why his approach might have been difficult for his wife to reconcile to:

> *That may not be a consideration for her, it may be "my husband's gonna die and what am I gonna do when I get older and this is just a sad life now" ... there has been this kind of potential dissonance.*

Lauryn described differences of opinion with her husband around sharing their cancer diagnoses with their children. Lauryn said she wanted to share with her children; however, she felt stifled by her husband's wishes:

> *It wasn't an easy time. I felt in a sense I was sort of suppressed because my husband didn't want to tell them ... we've had a few arguments about that over the months. I just felt in my heart that I wanted to do it.*

Lauryn went on to describe her experiences around her relationship with her husband's parents. Lauryn said her parents-in-law had always been supportive in the past, however have *"buried their heads in the sand"* in response to her diagnosis. Lauryn became emotional as she described her feelings about this dynamic:

> *My husband's father hasn't said anything to me about my diagnosis the whole 6 months that I've been going through this and I've found that really difficult to deal with. Same with his mum ... I feel like they've very much withdrawn from me ... someone you thought you were close with ... that's pretty disappointing.*

During the course of the interview dialogue with Denise, she recognised an aspect of her relationship and interactions with her 15-year-old son around her wellbeing that she wasn't previously aware of and perhaps needed her attention, describing it as *"more negative"* than the interactions she has with her daughter:

> *Reflecting now, I probably don't tell him as much of the good stuff, so might be something I need to change. Like, if I'm feeling good, I probably don't say it to him as much, it'll be more if I'm feeling bad, I'll say 'I'm actually feeling quite sick today, could you just give me a hand to do …', which I didn't realise until just then.*

Erin's terminal cancer diagnosis provided uncertainty for her and her husband, in relation to what time they would have together, and what her diagnosis could mean for future relationships in the family. Erin shared how her husband took 6-months leave from his employer following her diagnosis: *"We just weren't sure, crucial things were happening in that first 6 months … if we needed to spend as much time as we could together."* Erin went on to describe how the task of completing a will had become a more difficult and uncertain process than she initially imagined it would be, as it had ignited questions around future relationships for her husband and family, after her death:

> *Even things like wills. It's not as easy as I thought. If your partner remarries … I hadn't considered how that affects the kids and all that sort of stuff. That is a very real thing we need to think about.*

Erin also shared how the terminal nature of her illness had motivated her to take steps in enhancing her children's relationships with extended family members, particularly her sisters:

> *Having my kids interacting and building relationships with their aunties … it's for now, but it's also for their future, so that I know that they've still got that presence of me, parts of me, that are in them, going forward.*

A number of the participants spoke about the importance to them of love and support from others. Alex said he had been touched by the *"thoughts and wishes"* and *"empathy"* he had received from other family and friends. Ming expressed how the love and support he had received had helped him find new *"meaning"* and see his life had not been *"wasted."* Ming said the relationships in his family had become closer, as they *"fight together ... hold our arms together ... walk together."* Lihwa described how her relationship with her parents-in-law, who live with her and her husband, had changed since her diagnosis, having been a difficult relationship at times previously. Lihwa said the relationship had grown closer and that *"without them, I don't think I can get through all this."* Lihwa recounted particular moments with her parents-in-law in the days immediately after receiving her diagnosis, when they offered important acceptance and support to her. Lihwa described being very emotional at the time, however was concerned about expressing her emotions around other family members:

> *My mother-in-law let me express my emotion, she said it's okay, if you want to cry, just cry, it's okay. I'm glad that I can talk to my mother-in-law ... and my father-in-law said, if you feel upset or feel angry, just express your feelings, don't hold it, because it's not good for your body ... just let it out.*

This sub-theme captures a broad range of participant experiences around the changes and challenges their diagnosis and treatment prompted in their families. How the participants and their families responded and adjusted to the effects of these changes, and managed family life in the face of the participants' situation, is captured in the next sub-theme.

Dealing With It

During the interviews, the participants were able to share their experiences of enacted approaches, ideas, resources, and strategies, to help them and their family members navigate and respond to the changes and challenges presented by the participants' illness. The dominant approach described centred on the maintenance of normality, stability and consistency within the family's day-to-day existence and activities. This approach was particularly targeted at children, with the participants and their partners generally sharing in the task of *"providing suspension"* for the family - managing information about the parent's illness in order to moderate the impact upon their children. Such an approach at times required the creative application of ideas and strategies, generally self-directed, with some external resources also being referenced. Conversely, the participants who had struggled to communicate with their children regarding their cancer, recognised that their efforts to maintain stability required a level of vigilance. Thus, the openness or otherwise in which the participants and their families communicated about the parent's cancer was a determining factor in how they maintained normality.

The participants described the approach of maintaining normality and stability within the family as striking a balance between open communication with children about the parent's illness, and managing the *"transmission"* of information so as not to cause children worry or alarm. Alex spoke about such an approach, and how his wife had assumed the lead role in putting it into action:

> *We do a good job of providing suspension for the kids, we try to minimise the impact of news. They can't process ups and downs ... they're very much responding to my wife's portrayal of the situation, her emotions, her description of it all, and what we're trying to do is just keep everything stable and balanced. We talk about it, but not in a negative or scary way.*

Similarly, Denise described how, from the outset, she and her husband portrayed for their family a sense of *"routine"* around her diagnosis and treatment, in order to maintain a stable environment: *"With the kids they kind of followed suit. We're a very calm household, all of us are quite calm and take things as they come ... probably I was shielding them, and at the same time probably myself."* Erin described how maintaining the routines within her family and her children's expectations allowed for a sense of consistency and stability, even given the seriousness and demands of her illness. Erin spoke of her absences due to treatment appointments and hospitalisations, and steps she had taken to mitigate disruptions in the family, such as taking photos of her children's usual school lunches for her husband; and arranging play dates with school friends *"so my kids got used to those parents' faces."* Erin said it was important for her children that they *"still saw my face around the house"*, and continued to receive the meals they normally expected from their mother, rather than meals prepared by other people wanting to help, as Erin explained: *"Having their meals, the same meals, which sounds so ridiculous, but trying to feed them somebody's gnocchi, when the kids have never seen gnocchi before, that would be the meltdown point of the house."* Erin also explained that the babysitting arrangements for her usual work days had been kept in place, meaning the children spend 3 nights per week with Erin's mother-in-law:

> *That normality and consistency ... that works well if I did go into hospital, they're set up there, that's normal for them, it's less of a shock. The fact that mum is in hospital for 5 days is neither here nor there if the main things are still happening.*

Lauryn and Erin described the vigilance they applied at home in order to maintain a stable environment and protect their children from distress around the illness situation. Lauryn spoke about her awareness of what her children might see or hear: *"I was very protective of my phone in case someone called or messaged and it was something that they'd see, or there was no literature hanging around."* Similarly, Erin was concerned about what her children may overhear or witness when people visited the home:

> *I am conscious of parents and friends coming ... talking with them they get upset about the situation, so it's just trying to be mindful of where my kids are so they're not seeing that interaction which could be stressful for them, seeing an adult upset about whatever's going on.*

During the interviews, a number of the participants shared their experiences around creative examples of ideas and strategies they implemented to deal with the challenges of the participants' cancer situation, in order to help the family and individual family members cope and adapt. Several of the strategies described were focused on helping to *"keep things normal"*, though some strategies were applied to help open up the dialogue with children about cancer, involve children and extended family in participants' treatment and wellbeing, and *"take that whole fear out of it."* Some participants described making use of external resources, however these were generally sourced through their own initiative, or with the help of other family members.

A number of the participants described using a *"light hearted"* approach towards involving their family members in the physical effects of their cancer treatment. Denise described holding two parties with her immediate and extended family:

> *We turned it into a wig party, where we tried on the wig and everyone had photos, and that was fun ... so it was out in the open. But having the shaving party for all of us, for me especially, but I think my nieces, my nephews, my own children ... was a huge, positive thing to do.*

Erin described a number of approaches she enlisted in order to involve her children in her treatment experience, and open up the dialogue around her illness. These included such ideas as giving her 6-year-old son the daily job of choosing a flavoured supplement she was required to take after a surgical procedure: *"He loved it, he'd come in, 'Are you ready for it yet? What flavour would you like?'" So, it was his little way of helping."* Erin also allowed space to spend time with her children when she came home after treatment: *"I've got the medicine attached ... let them see it and ask questions if they've got any."* Further, Erin used a book sourced by her sister, written by a cancer patient and illustrated by the patient's child, which Erin would read with her two oldest children: *"and asked them if they had questions* *about things and it had words like chemotherapy and treatment, having medicine that makes you sick to make you better ... to open up the dialogue."* Rebecca also described using a book resource to help her 10-year-old son better understand his mother's treatment, as well as informing her son's school about her illness, enlisting the ongoing support of the school chaplain for both she and her son. Additionally, Rebecca said she had arranged professional counselling for her son, out of concerns for his emotional wellbeing: *"I don't want him to squash this all down, I don't want him to have separation anxiety, and I don't want him to lose confidence in just who he is."*

This theme relates to the participants' experiences of their cancer diagnoses and ongoing treatment, within the context of family and relationships. The participants' described the changes they had experienced and noticed within the family since being diagnosed with cancer and commencing treatment, as well as the approaches and strategies they have applied to help the family talk about, and cope with, the implications of their illness, with much of the participants' focus being on their children. The participants' experiences and insights at a more personal and intimate level, are reported in the final theme to emerge from this study.

5.3 Theme 3: Playing the Hand You Are Dealt

The third theme to emerge from the data analysis, captures the participants' experiences and insights as individuals continuing to live their life in the face of their cancer diagnosis, treatment and outcomes. During the course of the interviews, the participants referenced personal and fundamental aspects of their lives which had helped or hindered them during their time with cancer. The participants described their experiences and struggles in relation to the acceptance of their situation; resilience in the face of the physical and emotional challenge of cancer; and how their self-concepts in relation to identity had been impacted. These personal experiences are detailed in the following three sub-themes.

Acceptance

This sub-theme encompasses the participants' experiences and insights around coming to terms with having cancer in their lives. For some participants, acceptance was difficult to cultivate in the early days of their diagnosis and treatment, however a gradual acceptance of cancer being a part of their life helped them cope with the *"good days and bad days."* Some participants described the acceptance and *"peace"* they found through their spiritual and faith-based beliefs. Further, cancer treatment, whilst difficult, was accepted as being a pathway back to a normal life. For other participants, particularly those faced with a terminal cancer diagnosis, experiences of struggle in accepting the situation were shared.

Alex described how upon first receiving his diagnosis, he dwelt on regret about not acting on his health concerns sooner, and feeling alone in his situation: *"Early it's only me, I'm the only one in the world. What's happening, why me? I'm fit and healthy and young."* Alex went on to define his growing acceptance: *"Yeah, just dealt a very bad hand, you know, but play the hand you're dealt."* Similarly, Denise described her acceptance of the situation and the day-to-day fluctuations in her wellbeing: *"It's definitely part of our life ... I have good days and bad days, mostly good."* Lihwa described how learning more about her diagnosis and likely outcome allowed her to accept and reframe her treatment regimen: *"After my research [and] scan ... I accepted that, okay, I need to do this surgery, I need to focus on my treatment and then after everything's done, I can be a normal person again."* In contrast, Ming described how reconnecting with his spiritual faith to help cope with his situation had brought him a sense of peace and acceptance he described as *"a supernatural power."* Likewise, Shivnath described how his spiritual beliefs allowed him to accept whatever the future brought, and to appreciate each day, as he described:

> *There's no point in thinking, what is going to happen tomorrow ... I'll be losing my precious time which is in my hand now. I want to enjoy this time. I don't want to lose this time worrying about what is going to happen in the future.*

Some participants shared their struggles with accepting their cancer situations. Erin, faced with a terminal diagnosis, shared how acceptance of her situation has been a struggle, particularly given her past commitment to personal health:

> *I think just being young, fit and healthy … it was a long time to get our head around it and I guess even still, I'll have days where I feel well and it seems the whole idea of it seems a little bit ridiculous, to be honest. It's the only way I can explain it.*

Erin went on to describe how she was impatient for acceptance in the early days of her diagnosis, and how she learnt that acceptance takes time:

> *I think I was in a hurry at the beginning to be mentally fast tracked to that place where you're at peace with what's going on for you. But it's that realisation that it's very much a process … it's up and down … it's just the realisation that's just the way it's gonna be.*

This sub-theme relates to the participant's experiences and struggles around the cultivation of acceptance as to their cancer situations. The participants also shared their experiences around coping on a day-to-day level with the physical and emotional toll of living with cancer. These experiences are the subject of the next sub-theme to be presented.

Resilience

During the interviews, a number of the participants spoke about their experiences, attitudes, and insights as to their resilience in coping with the physical and emotional toll of living with cancer, and all it entails. For some participants, a focus on physical health and self-care were referenced as factors in cultivating and enhancing resilient attitudes and confidence; whilst for others, hope and optimism were described as fundamental drivers of resilience. In contrast, some participants described how their capacity for resilience has been tested by the physical and emotional demands of cancer treatment and setbacks, resulting in personal struggles.

A number of the participants spoke about their general attitude to life and how this helped to replenish their reserves of resilience. Lauryn described how her tendency for action and a positive outlook has helped her manage the challenges she has faced:

> *I don't like sitting down dwelling on things, I prefer just to get up and do things, carry on as normal as much as I can. But I haven't lost my hair … I have been able to maintain some sort of lifestyle, I continued working for as long as I could. I think overall it's been okay.*

Some participants spoke about the importance of self-care in helping them to manage the physical impacts of their treatment, and to foster a sense of self-efficacy and confidence. For example, Alex spoke of how his healthy appetite and regular exercise helped to grow his self-confidence and self-image: *"That to me doesn't say cancer sufferer, someone sliding food down and going for walks in the sun and all this kind of thing. That says you're fine, you're going through this, it's not defeating you."* Similarly, Lihwa shared how her daily light exercise schedule had helped improve her physical and mental health, and her outlook: *"After I started doing this light exercise, I felt much better, you know, you sweat a little bit and then emotionally, you're gonna feel positive and much better."* On the other hand, Ming offered a different view of self-care, describing an attitude of self-kindness when feeling *"quite useless"* for not being able to contribute more in his family, due to the physical demands and side-effects of his treatment. This seemed to enable Ming to find meaning in his physical suffering, and to promote optimism:

> *Maybe it's time for me to take a break and focus on what's more important, which is the treatment, to keep myself well, so that I can recover faster, and contribute more after … for the family. The resting time you are doing now, is not meaningless, it still has a purpose … your resting is actually helping you to move on in your future.*

Hope and optimism were described by a number of participants as important factors in enabling them and their families to cope, not only with the immediate physical and emotional challenges posed by the participants' treatment, but also the possible outcomes. Alex shared how his treatment engagement with the cancer treatment centre had provided him with a sense of *"comfort"*, and optimism around coming out the other side of his cancer journey:

> *You're not the only one with the issue. To be in this sort of community ... people finishing their treatments, hearing stories for the first time about success and coming out the other side of it. That gives me comfort ... there are other people going through this.*

During his interview, Shivnath consistently referenced hope and optimism as key factors for him and his family in fostering resilience in the face of his stage 4 cancer diagnosis. Shivnath spoke of a focus on his physical health, his spiritual practice, and the strong support of his family, as giving him confidence and hope for the future: *"Somehow, I have confidence in myself, I'm going to defeat this disease and I'm going to survive ... and that confidence is actually pushing me high and resulting in so many positive things around me."*

Contrasting with the above experiences, some participants described their struggles and challenges in continuing to respond to their cancer situations resiliently. Erin described her first 6 months of treatment as *"brutal"*, saying she focused on getting through it as she believed her treatment would then be over. Erin spoke of her struggles when learning that her treatment would be ongoing:

> *When I was told ... there's never going to be an end to it ... I felt like I was going through that whole thing again, the whole process of grief and shock and everything again. Being faced with the reality of what life will be going forward.*

Erin also described a counselling engagement, in which the counsellor was *"a bit of a* *cheerleader, saying 'You might be the one in a million.'"* Erin described how this was *"false hope"* for her: *"For my personality, that was not doing me any benefit at all, because that was just false hope of something that wasn't going to happen ... not wanting to get my hopes up again."* Rebecca described herself as *"a very resilient person"*, yet shared her struggle with the physical impact of her treatment, and how it took away her capacity to manage her emotional wellbeing: *"I need a bit more now on my emotional wellbeing, because my physical's depleted. I'm tired, I'm not as resilient as I was, because I can't do the physical things to just pound out stress or anxiety."*

This sub-theme represents the participants' experiences and struggles in relation to their resiliency in dealing with the day-to-day challenges of their cancer journeys. The participants also shared their insights and learnings in relation to their self-concepts, and how these have been impacted or changed in the course of their cancer experiences. This aspect of their experiences is described in detail in the final sub-theme below.

Identity

During the interviews, a number of participants spoke about the challenges they had experienced in terms of their self-concepts, or identities, due to the demands of their illness. For some participants, particularly mothers, these experiences centred on their lost capacity to fully engage in the role or roles that defined who they are, whilst others shared their concerns around losing who they are by being defined as a cancer patient. In the midst of these difficulties, some participants shared learnings about themselves as a consequence of their cancer diagnoses, allowing them to set new directions and priorities in their lives.

For the participants who were mothers, the loss of their identity as a mother was keenly felt and described. For Lihwa, the consequences of being diagnosed with breast cancer only days before the birth of her second child robbed her of some fundamental motherhood experiences with her newborn child, such as breastfeeding, leading to emotional feelings of inadequacy as a mother: *"It's like you're not you, you always provide the best that you could, but this time I had no choice."* Erin spoke of how the physical impacts of her treatment had stopped her from being involved in many day-to-day family activities that represented *"quality of life"* for her. Erin described her role as a mother, and her work in the health sector, as essential aspects of her identity, equal in importance to her own wellbeing:

> *I feel like my main job, besides getting better and looking after myself, is to focus on my kids. I don't want to sit around doing puzzles 24/7, I want to be involved in their lives ... that's what a mum does, that's my primary role besides, well being able to work, so work is very much part of my identity and if that's completely gone, the other part of me is being [a] mum.*

Some participants spoke about a sense of stigma being attached to their cancer diagnosis and becoming a cancer patient. Alex described his strong conviction to embrace his authentic self and not be defined by cancer, whilst acknowledging the stigma he felt in the early stages of his diagnosis:

> *I don't want this to define me, this is just a problem in the background, I'm me and I'm gonna be more me than I ever was ... but in some ways it's almost a stigma feeling, that you are the only one ... oh, you've got cancer.*

Shivnath also described experiences of a felt sense of stigma around being seen as a cancer patient, and how it could *"derail"* him from focusing on his health and wellbeing:

> *If I tell someone I'm a stage 4 cancer patient, the treatment that the other person will give to me is different, it will not be normal ... and I don't like people showing pity on me ... oh, you are a cancer patient, sit here, eat this, eat that. That keeps reminding me that I am a cancer patient.*

For some participants, their journey with cancer had presented opportunities to address aspects of their identity and develop fresh understandings around their approach to living, setting new directions and priorities in their lives. Alex spoke in detail about his life prior to cancer, describing himself as being *"a little bit nervous"* and only *"half living"* his life. Alex described his *"eureka moment"* in response to his cancer diagnosis:

> *I'm buggered if I'm gonna pretend anymore, and try to fit in, and say the right thing because I think I should ... I want to be true to myself and live how I actually wanna live, and reduce the influence of external pressures to adjust what my natural happiness and contentedness and life would be.*

Alex went on to describe how he has become more engaged with his family, and life in general: *"My mindset's been very much to really value every day and engage with life, engage with the family and the kids and everything and make the most of it."* Similarly, Ming spoke about a change in his priorities as a consequence of his cancer experience, having previously lived a hectic life focused on wealth accumulation and success:

> *This illness gave me a chance to reorganise my life, because I did not stop, and I wouldn't stop, until something really bad stopped me ... this cancer. So, it's given me time and courage to review my life and try to set it back to the right order.*

5.4 Summary of the Findings

The depth of data provided by the participants in their interviews, resulted in an extensive presentation of the findings that emerged from the data analysis endeavour. Hence, for purposes of clarity before engagement with the Discussion section of this thesis, a summary of the key findings follows.

Theme 1: Hearing the Words "You Have Cancer"

The findings presented for this theme related to the participants' experiences in the immediate period of learning of their cancer diagnoses, including the medical necessity of becoming a cancer patient, and their emotional and cognitive responses to the diagnosis. The key findings to emerge were:

- The participants' immediate emotional reactions to learning they have cancer were shock, fear, and other complex reactions.
- In contemplating their diagnoses and mortality, the participants' cognitive responses were generally aligned with family concerns, such as what impact their potential death might have on family members, and taking steps to make sure the family was secure for a future without them.
- The participants described difficult interactions with medical professionals which eroded confidence and hope.
- The participants said it would have been helpful if emotional and psychological support had been made available as part of the medical engagement, including assistance in accessing ancillary services, and peer support opportunities.
- The participants noted there had been limited recognition, guidance or awareness raised by medical professionals around the potential impacts of their diagnoses upon their families.

Theme 2: Bringing Cancer Home to the Family

This theme presented the experiences of the participants within their immediate and extended family contexts, at diagnosis stage, and as their treatment and side-effects progressed. The main findings to emerge were:

- The disclosure of the initial cancer diagnosis and ongoing information about treatment were generally communicated openly with children, although some struggled with what to say, how to say it effectively and safely, and where to find helpful resources.

- The participants were uncertain as to how their children were coping emotionally and psychologically with the parent’s illness.
- The participants’ families were physically impacted by the participants’ diagnosis and treatment in various ways, such as the participants’ hair loss, the ill parent’s unavailability and altered routines, and children’s disturbed sleeping patterns.
- Other family members, particularly partners, assumed additional roles and responsibilities as a consequence of the participant’s situation.
- In the face of the illness, family relationships were enhanced by mutual support and emotional expression, and adversely impacted by dissonance, and emotional suppression or withdrawal.
- The dominant approach taken to help the family deal with the demands of the parent’s illness, was to maintain a normal, stable, and consistent household environment, particularly for children.
- Creative strategies to support children cope with their parent’s illness included involving children in the parent’s care and treatment, and using targeted resources to open the dialogue about cancer with children.

Theme 3: Playing the Hand You Are Dealt

The findings presented for this theme detailed the participants’ experiences and learnings around their personal journeys with cancer. The significant findings to emerge were:

- Spirituality, faith, and living in the present moment were factors in the process of finding acceptance and peace.

- Hope and a focus on physical health and self-care, were important elements for the nourishment of resilience. Emotional resilience was impacted by setbacks and physical depletion.
- Being unable to fulfill parenting roles, and being labelled a cancer patient, resulted in stigma and the loss of identity.
- Cancer offered opportunities for reassessing priorities and living more authentically.

6 Discussion

The aims of this study were to learn how parents and families are responding to the impacts of a parental cancer diagnosis, and determine if gaps exist in the support and guidance that parents receive in effectively managing such impacts. Many of the key findings of the study are consistent with previous literature relating to this phenomenon, with some findings offering significant substantiation to concepts around family communication, and family-focused oncological support of parents receiving a cancer diagnosis. In this Discussion section, I will link the key findings to emerge from the data analysis with the existing evidence within the literature. The discussions are delineated under three headings, informed by the thematic structure of the analysis and the experiences of the research participants namely, the immediate experience, the family experience, and the personal experience. Through this approach, I intend to demonstrate how the research questions have been answered, illuminate the significance of the study, and suggest opportunities for further research into important aspects of the phenomenon.

6.1 The Immediate Experience

The participants offered a pronounced sense of overwhelming emotions and thoughts they experienced in the immediate period of receiving their cancer diagnoses. The participants' experiences of shock, fear, and disbelief seem understandable in the circumstances, and similar reactions have been reported in the literature (e.g., Fisher & O'Connor, 2012). Further, the distinct somatic reactions described by Alex and Ming (e.g., feeling separated from the body, hot flushes, nausea), and Shivnath's immediate need to demonstrate strength in the presence of his wife and son, having just received his diagnosis in their presence, were possibly gender-aligned reactions (O'Neill et al., 2018; Rashi et al., 2015). The physical embodied experiences described by Alex and Ming may have been more associated with their gender than their role as a father with cancer (O'Neill et al., 2018), and Shivnath may have felt the responsibility for projecting a sense of strength for his family, informed by his fathering role (Rashi et al., 2015).

As the participants of this research contemplated the ramifications of their cancer diagnoses and mortality in this primary stage of their respective cancer journeys, the participants' emotional and cognitive reactions shifted to a focus on their families, in particular children, supporting the assertion by Huizinga et al. (2011) that "parental cancer is a family experience" (p. S243). The participants expressed sadness and loss around their possible or likely death and no longer being a part of their children's lives, irrespective of the stage of their cancer trajectory, and what impact this may have on their children - a response reported consistently in the literature (Fisher & O'Connor, 2012; O'Neill et al., 2018; Park et al., 2017; Semple & McCaughan, 2013; Turner et al., 2007a). Further, some participants focused their thinking at this time on the family's ongoing wellbeing and security, in the event of the participants' death. For example, Alex described getting his responsibilities for the family's administrative affairs in order and ready to pass on to his wife, and Shivnath wanted to use his remaining time to ensure his family was financially secure. These thinking patterns may have been reflective of a self-view as the breadwinner and defender of the family in the role of father (O'Neill et al., 2018). On the other hand, Erin’s long-term focus on her family’s future without her, suggests there may be other factors which determine how all parents, regardless of gender, may cognitively respond under such circumstances. For example, future planning around a family’s financial security in the event of a parent’s death due to cancer may be a way for a parent of any gender to continue their role of caring and supporting the family, particularly children, even after their demise (Fisher & O'Connor, 2012).

The experiences described by Erin, Shivnath and Alex, in relation to interactions with medical professionals from various sectors of the medical system, that they found distressing and impactful upon their confidence in the medical support they were receiving and hope for surviving the illness, highlighted an unexpected finding in this study which potentially holds significance for health care professionals across multiple levels. For Erin, Shivnath and Alex, the way they received the critical news of their cancer diagnoses, or received contradicting treatment information from oncology professionals, mattered (Butow et al., 1996; McClement & Chochinov, 2008). Importantly, rather than the purely medical aspect of such interactions, Lee et al. (2002) suggested that “the setting, the use of words, the nature of the physician’s emotional connection with the patient” (p. 464) are crucial factors in determining how a cancer patient subsequently adapts to, and copes with, their illness and treatment, and the effectiveness of the relationship between the patient and the health care professional. The notion of hope in the context of the cancer experience was referenced by a number of participants in this study (refer Section 5.3) and will be discussed further in this thesis (refer Section 6.3). Hope is a central component in the lives of parents and their families in the face of a cancer diagnosis (Chi, 2007), and health care professionals are centrally placed to promote, or inhibit, the cultivation of hope in their interactions with cancer patients (Lee et al., 2002; Lichwala, 2014). Cancer patients who experience adverse dealings with health care professionals may feel more distressed, and less optimistic and hopeful (Lichwala, 2014; McClement & Chochinov, 2008). Conversely, interactions characterised by sensitivity, education, and understanding may help to promote patients' levels of hope (Lichwala, 2014; McClement & Chochinov, 2008). The distressing experiences described by the three participants in this research around the manner in which they learned of their cancer diagnoses, or in relation to other interactions with health care professionals that diminished confidence, may be an indicator for further investigation into cancer patients' experiences of their connections with health care professionals involved in their care, and how this supports or inhibits their capacity to cope with the illness. These findings and concepts point to other more specific experiences around the professional guidance received by the participants in this study, and what would have helped the participants in their immediate medical engagement.

The participants in this study identified emotional and psychological support from health care professionals and ancillary services, from the outset of their medical engagement, as generally absent, as was professional guidance from health care professionals around the common impacts a parent's cancer diagnosis may have in a family with minor-aged children. Further, the participants specifically referenced that emotional support, such as counselling, would have been beneficial to them in the early stages of their cancer diagnosis. The literature has consistently supported the notion of guidance and psychosocial support for parents of minor-aged children when they receive a cancer diagnosis; specifically, the need for guidance around communication within the family about the diagnosis, particularly with children, has been extensively acknowledged (Asbury et al., 2014; Barnes et al., 2000; Ellis et al., 2017; Fisher & O'Connor, 2012; Hailey et al., 2018; Huizinga et al., 2011; O'Neill et al., 2018; Rashi et al., 2015; Semple & McCaughan, 2013; Turner et al., 2007a). The overwhelming and distressing nature of a cancer diagnosis, and the accompanying enormity of clinical information, likely compromised the capacity of participants such as Alex, Erin and Lauryn to have been emotionally prepared for the challenge of telling their children about the diagnosis (Hailey et al., 2018; Rashi et al., 2015; Schiena et al., 2019; Semple & McCaughan, 2013). Although oncology professionals are viewed as being ideally placed to provide psychosocial support, guidance, and tailored interventions in such circumstances, the literature suggests that oncology professionals evade discussions with parents about the impacts the illness may have upon their families, or providing guidance around how to communicate with children about cancer (Turner et al., 2007a).

The participants in this study referenced a number of services, resources, and general modes of guidance that may have been helpful to them, both individually and in a family context, upon receiving their diagnosis. Previous studies have also referenced these and other ideas. For example, Rebecca and Shivnath expressed how valuable counselling would have been for them and other family members, at the outset of their cancer experience (Rashi et al., 2015). Erin spoke of family counselling, peer support groups, and having an assigned case worker as services that would have been useful for her in the initial stages of her diagnosis (Barnes et al., 2000; Park et al., 2017; Rashi et al., 2015; Turner et al., 2007a). Ming said he would have appreciated hearing stories about how other families have adapted and coped with a parent’s cancer diagnosis (Turner et al., 2007a). Participants in the study by Turner et al. (2007a) said that hearing “authentic and valuable” stories from other families would be “empowering” (p. 141).

Notwithstanding the above findings, it may be that the concept of family-focused and medically initiated support and guidance for parents with cancer is a more complex issue and is subject to the unique circumstances and specific needs of each parent and their family

(Rashi et al., 2015). Some parents with cancer may prefer to rely on their own assessment and knowledge of their family and their circumstances, rather than accept external guidance, such as in Lauryn's rejection of a hospital practitioner's advice around communication with her children, and Denise's lack of engagement in discussions with health care professionals around how the family is coping (Asbury et al., 2014). Further, the provision of ancillary services such as counselling may not always be appropriately tailored for parents with cancer, leading to difficult and unhelpful experiences. For example, Erin's counselling experience, in which the counsellor did not seem to grasp the reality of Erin's advanced disease, prognosis, or what she needed (Turner et al., 2007a), instead persisting with the promotion of "false hope" (O'Hara, 2011, p. 325). Other examples of shortcomings in the support and resources available to parents with cancer have been noted in the literature. For example, Rashi et al. (2015) described a participant's experience with a resource book for children that spoke about such things as hair loss, upsetting the participant's daughter, even though the participant's particular treatment regimen would not result in hair loss. Sinclair et al. (2019) reported that women with breast cancer found the experiences and perspectives of peers to be confusing and impractical. In addition, health care professionals engaged in the care of parents with cancer may not feel as well placed to provide psychosocial support and guidance as has been suggested in the literature, and may also consider that parents' capacity to effectively access any suggestions for external family support services would be inhibited by the overwhelming nature of the cancer diagnosis and the accompanying volume of clinical information (Sinclair et al., 2019).

At a fundamental level, cancer patients who are parenting minor-aged children, particularly mothers, should be acknowledged by health care professionals as parents as well as patients (Fisher & O'Connor, 2012). However, in the findings of this study, Erin spoke of her care as being fully structured around a "biomedical agenda" (Ford et al., 1996, p. 1517), and recounted an experience which she felt dismissed the significance of her role as a mother (Fisher & O'Connor, 2012; Schiena et al., 2019). Further, Erin's proactiveness in sourcing pain management treatment from a palliative care doctor and her reluctance to discuss this with her oncology team, again raises questions around the purely clinical focus in the approach to parental cancer, and the relationship between the patient and health care professional. Medical recognition of a cancer patient's role as a parent, particularly for parents with a terminal diagnosis, such as Erin, can influence treatment strategies to limit the impact upon the parent and their family (Park et al., 2017). For example, prescribing pain management treatments for cancer patients with young children that minimise drowsiness at times when the role of parent is most important, such as during the day (Park et al., 2017). Further, Erin's reluctance to discuss pain management with her oncology team, out of a sense of disappointing them, evokes the notion of power in her relationship with the health care professionals involved in her treatment. As discussed earlier in this thesis (refer Section 3.1), the oppressive nature of power in society can suppress and marginalise individuals (Carr, 1998), and in Erin's case, she may not have felt capable of expressing her concerns to the medical experts. Some participants in this study spoke of receiving family-focused support from a breast care nurse, however this would be specific to breast cancer patients only, usually within the immediate period of diagnosis and surgical procedures.

Taken as a whole, the experiences and contradictions discussed here raise questions as to the viability of a *one size fits all* approach to family-focused oncological care, support and guidance; what such an approach might look like; and what oncology professionals in the front-line of cancer care, already dealing with the many facets of delivering critical clinical care in a dynamic medical setting, can effectively deliver for parents and their families dealing with a parent's cancer diagnosis.

6.2 The Family Experience

The immediate challenge the participants in this study faced in the context of family, following their diagnosis, was how to communicate with their children. Communicating with children about a parent's cancer diagnosis is a confronting test for parents, and is a crucial aspect in how children and adolescents adjust to the impacts of the illness (Huizinga et al., 2011; Schiena et al., 2019). A number of studies have highlighted that parents' need to protect children is a major influence in how a parent's cancer diagnosis is disclosed and discussed in the family (Asbury et al., 2014; Hailey et al., 2018; Lalayiannis et al., 2018; O'Neill et al., 2018; Rashi et al., 2015; Semple & McCaughan, 2013). The approaches taken towards communication by the participants in this study were self-directed, and reflected a variety of understandings, ideas, and motivations. For example, preparing children for the physical and visible side-effects of the parent's cancer treatment, such as having a mastectomy, or hair loss due to chemotherapy, motivated Lihwa to speak openly with her daughter about her diagnosis and treatment (Hailey et al., 2018; Rashi et al., 2015). For some participants, for example Ming, communicating honestly to the family, particularly children, about how they were feeling physically was important, as it helped to alleviate uncertainty and worry for the children (Barnes et al., 2000).

For two participants in this study, Erin and Lauryn, communicating with their children was challenging and distressful, particularly while dealing with their own emotional reactions as they struggled to come to terms with their diagnoses. Much of this turmoil and uncertainty resolved around balancing the need to inform their children about the illness in an appropriate and age-specific manner, while also not wanting to overwhelm the children emotionally (Sinclair et al., 2019), particularly around the subject of death (Barnes et al., 2000). For Erin, her diagnosis of advanced cancer and the terminal nature of her prognosis made it difficult and upsetting to discuss the full extent of her diagnosis with her children, out of concern for how they would react, and if their age would preclude their comprehension of the concept of death (Fisher & O'Connor, 2012; Hailey et al., 2018). For Lauryn, who was already dealing with her husband's recent terminal recurrence of cancer, receiving her diagnosis was too overwhelming to immediately attempt the task of telling her children in an age-appropriate way (Semple & McCaughan, 2013). Erin and Lauryn went on to describe the vigilance and effort they exerted in ensuring their children did not inadvertently overhear discussion or read information about the illness, requiring much "closed doors" and "whispering" (Semple & McCaughan, 2013, p. 223). Nevertheless, children can be sensitive to changes in the family (Semple & McCaughan, 2013), and withholding age-appropriate cancer disclosure from children may result in them having misapprehensions about cancer that are more distressing than their parent's actual situation (Ellis et al., 2017). Further, avoiding honest and open communication in the family about a parent's cancer and the threat it poses may impact the capacity of children to cope with the illness, and lead to short and long-term feelings of exclusion and anguish (Finch & Gibson, 2009; Turner et al., 2007a).

The concept of open communication within the family was favoured and practiced by many of the participants in this study, though for most of the participants this practice did not appear to include honest and open *emotional expression*. For example, Alex, Rebecca and Denise, who championed open communication with their children, did not know how the children were coping emotionally with their parent's illness (Huizinga et al., 2011). This suggests that the information being disclosed may have been factual and minimised details of the diagnosis and treatment only, perhaps to avoid talking with the children about how they are feeling emotionally (Asbury et al., 2014; Fisher & O'Connor, 2012). Further, emotional expression was not favoured or explored by some participants, preferring to manage illness information and maintain a calm and positive approach, perhaps as a strategy for protecting their children from torment and maintaining a sense of normality in the family (Asbury et al., 2014; Barnes et al., 2000; Lalayiannis et al., 2018; Rashi et al., 2015). Paradoxically, the practice of emotional regulation by some of the participants may have served as a model of emotional suppression for the children, meaning the children did not share their fears or ask questions about their parent’s illness, so as not to cause the parent distress (Ellis et al., 2017; Huizinga et al., 2011). Moreover, the need to protect children and maintain normality may have resulted in the participants feeling duty-bound to uphold a “positive attitude”, which in turn may have hindered emotional expression for both the participants and their families (Turner et al., 2007a, p. 140). Hence, families that practice the open expression of emotions may suffer less distress (Harris & Zakowski, 2003). For Lihwa and Ming, the open and honest expression of emotions with other family members provided them with emotional release and closer family bonds, with family members treating each other with greater kindness and empathy in their shared experience of the illness (Finch & Gibson, 2009). Theoretical concepts in family therapy, such as Bowen’s Family Systems Theory, may provide a framework for understanding how the participants and families represented in this study promoted or suppressed emotional expression by family members (Bowen, 2019). Thus, from the findings described in this study, it would appear there is more to the concept of open communication than keeping family members informed about factual details. The findings in this study suggest that more awareness needs to be raised around the importance of honest and open emotional expression in families dealing with parental cancer. As noted earlier in this thesis (refer Section 3.1), how a family responds emotionally to a parent’s cancer diagnosis, and the level of support and engagement with the parent during their treatment, can significantly influence the parent’s resilience and wellbeing (Hartmann et al., 2010).

The very nature of cancer and cancer treatment induces physical changes and disturbances, for both the cancer patient and the family (Buchbinder et al., 2009). In this study, the participants described several direct and indirect physical consequences of their cancer diagnoses and treatment. Denise, Lihwa and Rebecca described the physical side-effects of treatment, in particular hair loss, as tangible evidence of the illness, and a potential source of distress for their children (Finch & Gibson, 2009). Alex and Ming spoke of disruptions to regular family activities and family holidays, due to the treatment demands and side-effects of the illness impacting their availability and involvement (Buchbinder et al., 2009; Fisher & O'Connor, 2012; Hailey et al., 2018; O'Neill et al., 2018; Park et al., 2017; Rashi et al., 2015). The changes in roles and responsibilities described by the participants, whereby family and friends assumed supportive roles often the responsibility of the participant, such as Denise's daughter taking on a mothering role for Denise's teenage son, have been highlighted by a number of studies in the literature (Buchbinder et al., 2009; Huizinga et al., 2011; Lalayiannis et al., 2018; Rashi et al., 2015; Schiena et al., 2019). A particular change described by some participants, including Erin, Ming and Shivnath, was the increased burden of financial and practical responsibilities placed upon their spouses, in order to ensure the continuation of normal family life while the participants were incapacitated by their illness (Rashi et al., 2015). Several physical changes and disturbances in young children and adolescents were also observed and described by the participants in this study, such as the changes in bedtime and sleeping patterns described by Lihwa and Rebecca, which involved a sense of "clinging" and an increased need for physical closeness, such as sleeping in the parent's bed (Visser et al., 2004, p. 688). Erin described the impact on her sense of attachment with her 5-year-old son, following the emotional disturbance of her emergency hospitalisation (Schiena et al., 2019). Denise recognised that the levels of frustration exhibited by her adolescent son had increased since the physical evidence of her illness had become noticeable. Emotional difficulties for adolescents, such as frustration, may be related to changes in roles and responsibilities in the family, whereby they are expected to perform more household tasks, conflicting with the developmental need for independence (Huizinga et al., 2011).

The participants in this study described a range of experiences around changes in their relationships with other family members because of their illness. The dominant experience of participants was characterised by support and renewed closeness in family relationships, particularly in families where the illness was spoken about openly (Buchbinder et al., 2009; Finch & Gibson, 2009; Huizinga et al., 2011). On the other hand, some participants described difficult or troubling relationship impacts, such as Lauryn’s descriptions of disagreements with her husband around communicating about cancer with their children, and the distancing of the relationship with her parents-in-law. Such relationship disturbances may arise when the longstanding patterns of support, accountability, and commitment which underpin family relationships are disrupted by a critical event such as a cancer diagnosis, instigating doubts around such things as responsibility for support and displays of emotional expression (Gibson et al., 2018). Upsetting relationship disturbances in families contending with a parent’s cancer diagnosis suggest that the concept of care in such circumstances is greater than simply discerning roles and responsibilities in the family – “it arises out of emotional relationships” (Gibson et al., 2018, p. 911).

The fundamental approach to managing the impact of cancer upon the families of the participants in this study, was to maintain normal routine and structure in the family on a day-to-day basis (Fisher & O'Connor, 2012). This approach was targeted primarily at protecting the children from upheaval and distress (Park et al., 2017). A number of previous qualitative studies into aspects of parental cancer have also identified the maintenance of normality, grounded in the notion of protecting children and helping them to feel more supported, as the central strategy adopted by parents and families in dealing with a parent’s cancer diagnosis and treatment (Fisher & O'Connor, 2012; Park et al., 2017; Schiena et al., 2019; Turner et al., 2007a). As previously noted, parental management and monitoring of cancer information and the parent's own emotions, were key components used by the participants in this research in their adoption of this strategy (Asbury et al., 2014). However, other basic steps were also taken by the participants to mitigate their absences from daily family functioning, particularly for mothers, for example organising help from other parents with school transport (Fisher & O'Connor, 2012), maintaining an active presence in the home, particularly at important times (Buchbinder et al., 2009), and children still receiving their mother's meals (Fisher & O'Connor, 2012). It appears that completing the task of organising steps such as these allowed the mothers in this study to maintain a connection with their parenting role, albeit in a more restricted capacity (Fisher & O'Connor, 2012).

In addition to maintaining normal family routines, the participants in this study used a number of self-directed creative strategies to instigate dialogue with their children about cancer and medical treatment, and involve children in their parent's care (Turner et al., 2007a). Denise's strategy of holding wig and shaving parties with her children and extended family appeared to have assisted her family to better understand the illness and treatment demands (Turner et al., 2007a). Involving children in specific care duties, such as Erin's 6-year-old son's task of choosing a daily supplement, can provide children with a sense of inclusion and help them to feel less helpless (Turner et al., 2007a). Erin's approach of setting aside special time after her treatment for her children to ask questions, and Erin and Rebecca's use of book resources to promote open dialogue with their children, can help to alleviate children's worries and uncertainty about what is happening for their parent (Buchbinder et al., 2009). Importantly, involving children in their parent's care may also provide parents with a renewed "sense of purpose" in confronting their illness (Buchbinder et al., 2009, p. 222).

6.3 The Personal Experience

The descriptions offered by the participants in this study, as to the personal experiences, insights, and learnings arising from their journeys with cancer, indicate a juncture between the profound emotional anguish of being diagnosed with cancer, the cultivation of hope and resilience, the impact of the illness on parental identity, and the opportunities for personal growth (Thornton & Perez, 2006; Yang et al., 2010). Some of the participants in this study, for example Ming and Shivnath, spoke of the rekindling of their spiritual and religious faith, and a deep revolution of their relatedness to living in the present moment without worry for the future, as instrumental in fostering acceptance and hope and alleviating distress, in the face of their life-threatening crisis (Park et al., 2017; Yang et al., 2010). Moreover, Shivnath referenced the importance to him of the close and supportive relationships within his family in nurturing and preserving hope, and cultivating his resilience in coping effectively with the illness demands (Chi, 2007).

The participants in this study described a number of resilient approaches towards the circumstances of their illness, building their capacity to cope with, and respond to, the difficult circumstances of their illness and treatment (Wang et al., 2022). For example, Alex and Lihwa described their focus on physical health through nutrition and exercise (Schiena et al., 2019), Lauryn spoke of maintaining a positive outlook (Chi, 2007; Johnson, 2007), and Shivnath expressed the strength and comfort he drew from the support he received from his family (O'Neill et al., 2018). For the participants in this study, it appears that their capacity for resilience was strongly associated with their level of hope and the supportive nature of their families and social networks (McClement & Chochinov, 2008; Wang et al., 2022). The findings of this study suggest that, regardless of the staging of the illness, hope was a critical factor for the participants in envisioning possibilities for the future, and helping to reduce distress, even when physical health was compromised by treatment effects (Chi, 2007;

Rustøen et al., 2010). Further, it appears that connection with, and support from, family and friends was essential for the enhancement of acceptance and resilience (Johnson, 2007; Wang et al., 2022). Conversely, the participants who suffered increased anguish and found it more difficult to cope with the impact of treatment and side-effects, may have had reduced levels of hope (McClement & Chochinov, 2008; Rustøen et al., 2010). However, it should also be noted that for those participants, the demands of cancer treatment, such as frequent hospital visits, side-effects, and generally feeling unwell, may have impacted upon the quality of their family connections and by extension, their resiliency (O'Neill et al., 2018). It would appear that the concepts of resilience and hope for parents with cancer are multi-faceted and are particularly associated with the strength of parents’ emotional relationships with those closest to them, and as discussed earlier, their working relationship with health care professionals (refer Section 6.1). Moreover, the strengthening of existing relationships through the cultivation of emotional expression and support appears to provide the opportunity for cancer patients to personally grow through their cancer experience (Thornton & Perez, 2006).

The “crisis of identity” that was felt and described by participants in this study - mothers and fathers - as a consequence of the illness and the demands of cancer treatment, may have arisen from a sense of having no control of the situation they were confronting (Yang et al., 2010, p. 63). The participants who are mothers described being unable to fulfill the normal function of being a mother due to the ongoing effects of treatment, thus eroding their self-concept as a mother (Buchbinder et al., 2009). For some parents, their employment was an important aspect of their identity, and being unable to return to work resulted in role disruption and confusion (O'Neill et al., 2018). In addition to the loss of identity due to the demands of cancer treatment, some participants also described feeling stigmatised and isolated in their social relationships (Fisher & O'Connor, 2012).

Notwithstanding the experiences of identity crisis described above, some participants spoke of positive changes in their self-concepts and attitudes towards the way they live their lives, and improved relationships with others, as a consequence of their cancer experiences (Johnson, 2007; Thornton & Perez, 2006). For example, Alex described his commitment to a richer union with his authentic self (Yang et al., 2010) and a fuller appreciation for what it means to be a father, resulting in a shift of his previous identity alignment with work to being more engaged in family life and relationships (O'Neill et al., 2018). Ming spoke of confronting a re-evaluation of his old priorities around material wealth and vocational achievement, moving towards finding joy and fulfillment in what he found most important in life (Fisher & O'Connor, 2012; Johnson, 2007; Yang et al., 2010). These experiences of participants finding a sense of becoming who they truly are and living authentically, may represent what Yang et al. (2010) termed a developed level of differentiation, and the culmination of the participants' spiritual journey with cancer.

7 Study Limitations and Recommendations for Further Research

This research encapsulated the unique experiences of eight people who were diagnosed with cancer whilst also parenting at least one child aged under 18 years, creating a vivid description of the challenges they and their families faced in traversing the personal and familial impacts of the diagnosis, and offering useful findings that help to expand knowledge and understanding around the phenomenon of parental cancer. Nevertheless, some study limitations are acknowledged, offering opportunities for further research. Firstly, each of the research participants were married and living with their partners, and were receiving cancer treatment from a private hospital cancer treatment service. Legitimate questions may be asked around how parents living under different contextual circumstances and parenting minor-aged children, such as sole parents, or parents from other socio-economic cohorts not holding private health insurance, might experience a cancer diagnosis and treatment, both personally and within their families. Further research into these and other cohorts of parents may assist in a further broadening of knowledge and understanding around this phenomenon. Additionally, the selection criteria applied to the recruitment of study participants is also acknowledged as a limitation in this study. All 8 participants in this study were in active cancer treatment, and all but one of the participants had been diagnosed with cancer less than 1 year prior to data collection. Further research that allows participants to expand upon their experiences over a more prolonged period of time, such as through the use of longitudinal diaries as a tool for data collection, should be considered (Scott, 2022). Such longitudinal research may add further depth and nuance to the experiences of parents and their families as they navigate a parent's cancer diagnosis over time, thus extending knowledge and understanding around this phenomenon.

Open communication in families about a parent's cancer diagnosis and treatment is a central element in how families effectively adapt to, and cope with, the changes and threats necessitated by a parent's cancer diagnosis (Turner et al., 2007a). As detailed in this thesis, the literature supports the notion that open emotional expression can reduce family distress, strengthen relationships, promote children's inclusion in their parent's treatment and care, and foster hope and resilience for the parent with cancer (Finch & Gibson, 2009; Harris & Zakowski, 2003; Hartmann et al., 2010; Turner et al., 2007a). However, for many of the participants in this study, open communication did not incorporate the open expression of emotions, either for the parent with cancer, or other family members; and often required the moderation or hiding of emotions by parents (Asbury et al., 2014). Such approaches were motivated by concerns around protecting children, or feelings of inadequacy in relation to appropriate communication (Hailey et al., 2018). Further research that specifically investigates the concept of open emotional expression in families dealing with a parent's cancer diagnosis, should be considered. Such research could also incorporate the investigation of the relationship between open emotional expression, family functioning, and hope and resilience for the parent with cancer. Moreover, such research could be informed by a systemic framework, for example Bowen’s Family Systems Theory, to gain knowledge and understanding as to how unique family emotional and relational factors may inform how families manage critical events, such as a cancer diagnosis.

The literature has consistently advocated for health care professionals involved in cancer treatment and care for parents diagnosed with cancer, to be proactive in raising awareness for parents around how a cancer diagnosis may impact the family (Arber & Odelius, 2018). However, clinical impediments that may inhibit health care professionals in providing effective guidance and interventions for parents diagnosed with cancer have also been recognised in previous studies (Dencker et al., 2017; Turner et al., 2007b), and health care professionals may not feel as well placed to deliver guidance as has been suggested in the literature (Sinclair et al., 2019). Moreover, contradictions in the literature suggests that support and guidance needs to be specifically tailored to the unique needs of each parent and family (Rashi et al., 2015). Further research should be considered to investigate the perceptions and experiences of health care professionals directly involved in the provision of cancer treatment for parents with cancer. Such research could incorporate oncology professionals’ understanding as to the challenges faced by parents when diagnosed with cancer, and how such understanding could be integrated into clinical care, and the working relationship with the parent. An extension of such research could involve an investigation into pilot programs, such as peer support groups and ancillary counselling services within a cancer treatment service; or an appropriately qualified liaison officer for assessing and coordinating the unique psychosocial needs of parents diagnosed with cancer, similar in nature to the role of breast care nurses. These research opportunities could represent a further contribution towards providing parents with cancer, and their families, with tailored and appropriate family-focused support. Such advances could potentially promote open emotional expression within families, reduce stress, enhance parent and family resilience, and ensure parents are seen as much more than simply a cancer patient.

8 Conclusion

The findings of this study indicate that, after more than 3 decades of research into the phenomenon of parental cancer, a diagnosis of cancer for a parent of minor-aged children continues to be a significantly challenging event for the parent and their family (O'Neill et al., 2018), with human experiences ranging from profound emotional distress through to more fulfilling relationships and personal growth. This research found that the need to protect children continues to motivate the ways in which parents and their families talk about a cancer diagnosis, and the strategies called upon to maintain stability in family life (Hailey et al., 2018; Park et al., 2017). Whilst much of the findings to emerge in this study have been extensively validated by previous studies into the phenomenon of parental cancer, questions have emerged around how families communicate emotionally about a parent’s cancer diagnosis, and what health care professionals involved in cancer care can realistically provide in relation to family-informed oncological care in medical settings. New research that views these questions through a systemically-informed lens will add further nuance to the complexities of emotional expression within families, and the provision of appropriate support and interventions that help parents and their families manage a cancer diagnosis effectively.

The findings of this study can have implications for practitioners across a number of fields. Medical professionals working in oncology or general practice, and practitioners working in ancillary cancer services (e.g., social work and counselling), may benefit through increased awareness around the particular family stresses cancer patients may experience when parenting young children. A recognition by medical professionals and ancillary practitioners of the systemic factors that may be associated with a parental cancer diagnosis has the potential to enhance the working relationship with their patients, aid in the provision of more family-focused cancer treatments and support, and cultivate hope and resilience for parents with cancer. Further, counsellors and therapists working in many therapeutic domains may encounter individuals and families who present with immediate and long-term issues in life, related to an experience of parental cancer. An awareness of systemically-informed theoretical frameworks and the factors that may contribute to difficulties, during and after such an experience, will enable counsellors and therapists to provide more appropriate and effective interventions, and promote positive therapeutic outcomes for their clients.

The completion of this thesis also brings to a close my reflexive journey over the course of my research endeavour. In the introduction to this thesis, I provided a personal reflection regarding my experience of the phenomenon of parental cancer, in order to disclose my intimate connection with the phenomenon, and to illustrate my motivation and rationale for the study. I wanted to know if the experience of parental cancer in my family was experienced by families confronted by parental cancer today. The findings of this study suggest that similarities do exist, in particular how parenting approaches and behaviours are informed by the need to protect children. I wrote the personal reflection prior to submitting my research proposal and receiving candidature for my study, and my reflexive practice operated parallel to the practical conduct of the study. Thus, it is important to conclude this thesis with a brief word on my experience of conducting the study, my personal position now in relation to the phenomenon I studied, and how I now view the experience in my own family.

Throughout the participant recruitment and data collection phases of the study, I was acutely aware of the challenges presented in recruiting and interviewing cancer patients in active treatment at a hospital cancer treatment service. Apart from the physical impacts of the illness and treatments, the existential realities that patients face in such a setting are telling –

existence, life and death, unfulfilled dreams. This experience challenged me to be adaptable, flexible, and above all else, understanding. This understanding was not just reserved for the participants in this study, it extended to the medical professionals – oncologists and nurses – who care for cancer patients. I witnessed firsthand the increased awareness around the offering of family-focused care that nursing staff exhibited, perhaps influenced by their awareness of my study. My perspectives around the role of oncology professionals in promoting family-focused care for parents with cancer has evolved since my introductory reflection, and I am hopeful that the findings of this study will lead to further research into how parents, their families, and the medical professionals entrusted with the care of parents with cancer, can be supported by appropriately placed and qualified ancillary cancer services.

Finally, over the course of the participant interviews, the fear and uncertainty experienced by parents when confronted by the challenge of talking with their children about the cancer diagnosis, and the implications for the parent, held significance for me. Given my personal experience, I devoted much reflexive practice to the paucity of honest and open communication and emotional expression experienced in my own family, leading to much reflection around what this meant for my sons. The difficulties in having such challenging discussions with children of varied ages are not lost on me, having experienced similar fears and uncertainties as reported in this thesis. Still, I witnessed the potential for closer family relationships, and the cultivation of hope and resilience, in my interviews with some of the participants who were emotionally open with their families. As I completed the research endeavour and finalised the writing of this thesis, this learning allowed me to sit with my two sons, now aged over 30 years, and talk about the experience in our family when their mother was dealing with advanced breast cancer. I have apologised to them for not sharing honestly about their mother’s diagnosis and illness progression, and they have acknowledged that they would have appreciated knowing, as it may have promoted different behaviours, and they could have spent more time with their mother. And, we have forgiven each other. The discussion was emotional and confronting, and we are even closer now for it. I am grateful to the research participants for sharing this learning with me.

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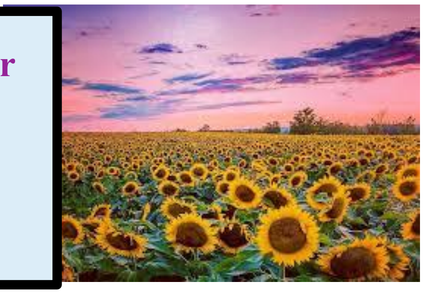
APPENDIX A

PARTICIPANT RECRUITMENT POSTER

Are you receiving treatment for cancer?



Do you have children aged 18 or under?

Are you interested in contributing to important research?

If so, please contact me on [redacted] or

george.prince1@my.nd.edu.au

George Prince, Research Student

THE UNIVERSITY OF NOTRE DAME AUSTRALIA

APPENDIX B

PARTICIPANT INFORMATION SHEET

What is the experience of parents who have been diagnosed with cancer whilst parenting minor-aged children: A phenomenological study

You are invited to participate in the research project described below.

What is the project about?

The research project will investigate how parents of children aged under 18 years, experience a cancer diagnosis individually and within their family. The project also seeks to understand what helps or hinders parents and their families to manage the impact of a parent's cancer diagnosis; and what part medical professionals play in supporting parents in such a situation. It is anticipated that the results of this study will be an important local and current contribution towards increased understanding around the impacts of parental cancer and the concept of family-focused cancer care.

Who is undertaking the project?

This project is being conducted by George Prince B.Couns and will form the basis for the degree of Master of Philosophy at The University of Notre Dame Australia, under the supervision of Dr Marieke Ledingham BSPsych, PGrad.Dip.Psych, M(Counselling), PhD and Professor Caroline Bulsara BA(Hons), Grad.Dip.Ed Studies, PhD.

What will I be asked to do?

You are asked to participate in a face-to-face interview about your experience in being diagnosed with cancer whilst parenting at least one child aged under 18 years. The interview will be conducted by George Prince. You will be provided with a copy of the interview schedule of questions prior to the interview.

The interview will take about 20 - 45 minutes and will be audio-recorded.

A summary of the interview will be posted or emailed to you for your information and validation.

Are there any risks associated with participating in this project?

Given the sensitivities associated with a cancer diagnosis and treatment, it is possible you may experience some level of anxiety or distress during the interview session as a result of some of the questions you will be asked. You will be monitored closely during the interview session and you are free to withdraw at any time during the session. We can arrange for you to access support from a pastoral care worker immediately following the session, or provide contact details for the Oncology West Clinical Psychologist for ongoing support, if required. There is no out-of-pocket expense for appointments with the Oncology West Clinical Psychologist.

What are the benefits of the research project?

By participating in this project, you will have the opportunity to engage in a safe and supportive interview process, allowing you to openly share your unique experience of being diagnosed with cancer whilst parenting at least one minor-aged child. Also, your participation will contribute to the aim of the project – to gain new and local knowledge and understanding as to the impact of parental cancer.

What if I change my mind?

Participation in this study is completely voluntary. Even if you agree to participate, you are free to withdraw from further participation at any time without giving a reason and with no negative consequences. You are also free to ask for any information which identifies you to be withdrawn from the study.

Will anyone else know the results of the project?

Information gathered about you will be held in strict confidence. This confidence will only be broken if required by law.

The audio-recording from the interview will be transcribed and stored on a password protected computer, with a back-up copy stored on an external hard drive secured in a locked safe. Only the researcher will have access to this information during the project.

Once the study is completed, the data collected from you will be de-identified and stored securely in the School of Arts and Sciences at The University of Notre Dame Australia for at least a period of five years. The results of the study will be published as a thesis.

Will I be able to find out the results of the project?

Once we have analysed the information from this study, we will mail a summary of our findings.

Who do I contact if I have questions about the project?

If you have any questions about this project, please feel free to contact George Prince at 0409 786 223 or george.prince1@my.nd.edu.au. Alternatively, you can contact project supervisor Dr. Marieke Ledingham at marieke.ledingham@nd.edu.au. We are happy to discuss with you any concerns you may have about this study.

What if I have a concern or complaint?

The study has been approved by the Human Research Ethics Committee at The University of Notre Dame Australia (approval number 2020-072F). If you have a concern or complaint regarding the ethical conduct of this research project and would like to speak to an independent person, please contact Notre Dame's Research Ethics Officer at (+61 8) 9433 0943 or research@nd.edu.au. Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

How do I sign up to participate?

If you are happy to participate, please contact the researcher, **George Prince**, at **0409 786 223** or **george.prince1@my.nd.edu.au**

Thank you for your time. This sheet is for you to keep.

Yours sincerely,

George Prince

APPENDIX C

THE UNIVERSITY OF
NOTRE DAME
AUSTRALIA

CONSENT FORM

What is the experience of parents who have been diagnosed with cancer whilst parenting minor-aged children: A phenomenological study

- I agree to take part in this research project.
- I have read the Information Sheet provided and been given a full explanation of the purpose of this research project and what is involved.
- I understand that I will be interviewed and that the interview will be audio-recorded.
- The researcher has answered all my questions and has explained possible risks that may arise as a result of the interview and how these risks will be managed.
- I understand that I do not have to answer specific questions if do not want to and may withdraw from participating in the project at any time without prejudice.
- I understand that all information provided by me is treated as confidential and will not be released by the researcher to a third party unless required to do so by law.
- I agree that any research data gathered for the study may be published provided my name or other identifying information is not disclosed.

Name of participant			
Signature of participant		Date	

- I confirm that I have provided the Information Sheet concerning this research project to the above participant, explained what participating involves and have answered all questions asked of me.

Signature of Researcher		Date	

APPENDIX D

Schedule of Interview Questions

What is the experience of parents who have been diagnosed with cancer whilst parenting minor-aged children: A phenomenological study

Primary interview question

- What has been your experience of being diagnosed with cancer?

Secondary interview questions

- What was your experience of sharing your diagnosis with your family and other close relationships?
- What changes, if any, have you noticed in your family since receiving your cancer diagnosis and commencing treatment?
- Has anything helped or hindered you and your family in responding to any changes? If so, what?
- Have the medical professionals involved in your care spoken with you about the common impacts of a parent's cancer diagnosis upon families? If so, can you tell me more about this?