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# Fathers of children with cancer: A narrative inquiry

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## Abstract

Receiving a diagnosis of childhood cancer can be a life-changing event for the child and their entire family. Parents of the sick child, in particular, are faced with the weight of responsibility for treatment decisions and caregiving, and often experience significant emotional, financial, social, and physical challenges during the treatment process. Mothers have traditionally been the focus of research in this area, and there is a paucity of in-depth, qualitative studies exploring the experiences of fathers, from their own perspectives.

The current study explores the experiences of fathers of children with cancer in Auckland, New Zealand. Recruitment of participants was carried out with the help of the local Child Cancer Foundation (CCF). Twelve fathers of children diagnosed with cancer within the last five years responded and participated in narrative interviews, in which they were also invited to bring along objects of significance. Data was analysed through a narrative analytic lens and a subsequent focus on roles: the ways in which fathers constructed a sense of self through the different roles embedded in their narratives. This focus on roles led to an exploration of the ways in which different roles of fatherhood and manhood were central to the ways in which participants constructed their experiences of being a father of a child with cancer. An exploration of the overarching role of Cancer Dad provided a framework to look at how this role was manifested through four key ideas: taking control, finding strength, juggling responsibilities, and managing relationships. Within the idea of taking control, the roles of Decision Maker, Active Advocate, and Practical Policeman are explored. In relation to finding strength, the roles of Emotional Rock and Lone Wolf are examined, and in regards to juggling responsibilities, the roles of Breadwinner and Caregiver are discussed. Finally, within the idea of managing relationships, fathers' constructions of the roles of Father, Husband, and Family Man are explored.

This study is important in its use of roles as a means of understanding fathers' experiences of their child's cancer, and its inclusion of objects and recognition of their significance as narrative devices which can enrich the research process. However, perhaps the most important contribution is to the advancement of some understanding of how fathers understand their place throughout the challenges of their child's cancer. Finally, this study also provides practical ideas for change, with the aim that support organisations and health professionals may provide more effective support services for fathers of children with cancer.

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# Table of Contents

|  |      |
|--|------|
| Abstract .....                                     | iii  |
| Acknowledgements.....                              | iv   |
| Table of Contents .....                            | v    |
| List of Figures .....                              | viii |
| <br>   |      |
| Chapter 1: Introduction .....                      | 1    |
| Introduction to the Thesis .....                   | 1    |
| Childhood Cancer .....                             | 4    |
| Childhood Cancer and the Family .....              | 9    |
| Siblings' experiences of childhood cancer .....    | 11   |
| Parents' experiences of childhood cancer.....      | 13   |
| Mothers' experiences of childhood cancer .....     | 16   |
| Fathers' experiences of childhood cancer.....      | 18   |
| Fatherhood and masculinity .....                   | 21   |
| Summary and Focus of the Current Study.....        | 23   |
| <br>   |      |
| Chapter 2: Methodology and Method.....             | 24   |
| Theoretical Framework: Social Constructionism..... | 24   |
| Methodology: Narrative Inquiry.....                | 25   |
| What are narratives?.....                          | 25   |
| Narrative interviews .....                         | 27   |
| Narrative analysis .....                           | 27   |
| Use of objects in narrative analysis.....          | 30   |
| Issues of reliability and validity.....            | 32   |
| Reflexivity .....                                  | 33   |
| Ethical considerations.....                        | 34   |

|  |     |
|--|-----|
| Method .....   | 35  |
| Participants .....   | 35  |
| Procedure .....  | 36  |
| Interviews .....   | 37  |
| Data analysis .....  | 39  |
| Summary .....  | 48  |
| <br>   |     |
| Chapter Three: Cancer Dad and Taking Control .....           | 49  |
| Cancer Dad .....   | 49  |
| Taking Control .....   | 53  |
| Decision Maker .....   | 53  |
| Active Advocate .....  | 57  |
| Practical Policeman .....                                    | 63  |
| Summary .....  | 72  |
| <br>   |     |
| Chapter Four: Cancer Dad and Finding Strength .....          | 73  |
| Finding Strength .....                                       | 73  |
| Emotional Rock .....   | 73  |
| Lone Wolf .....  | 79  |
| Summary .....  | 89  |
| <br>   |     |
| Chapter Five: Cancer Dad and Juggling Responsibilities ..... | 90  |
| Juggling Responsibilities .....                              | 90  |
| Breadwinner .....  | 90  |
| Caregiver .....  | 91  |
| Summary .....  | 107 |

|   |     |
|---|-----|
| Chapter Six: Cancer Dad and Managing Relationships.....   | 108 |
| Managing Relationships.....   | 108 |
| Father.....   | 108 |
| Husband.....  | 117 |
| Family Man.....   | 121 |
| Summary.....  | 124 |
| <br>  |     |
| Chapter Seven: Conclusions.....   | 126 |
| Summary of Findings.....  | 126 |
| Theoretical Significance.....   | 128 |
| Ideas for Change.....   | 131 |
| Limitations and Considerations for Future Research.....   | 135 |
| Reflections as a Researcher.....  | 136 |
| Concluding Comments.....  | 137 |
| <br>  |     |
| References.....   | 139 |
| <br>  |     |
| Appendix A: CCF Cover Letter and Participant Information Sheet.....                                     | 161 |
| Appendix B: Participant Consent Forms.....  | 164 |
| Appendix C: Summary of Findings for Participants.....   | 166 |
| Appendix D: Summary of Findings for Child Cancer Foundation.....  | 170 |
| Appendix E: Fathers of children with cancer: What to expect on the road ahead<br>[Brochure].....        | 176 |
| Appendix F: Beads of Courage: Narratives from fathers of children with cancer<br>[Journal Article]..... | 177 |



## List of Figures

|  |     |
|--|-----|
| Figure 1. A diagram showing a visual representation of the structure of my analysis, with Cancer Dad as the central role, surrounded by four key ideas with subsidiary roles.....  | 46  |
| Figure 2. A photograph showing the radiation mask used during Andrew's five year old son Alex's radiation treatment. ....  | 56  |
| Figure 3. A photograph showing Jack's son Matthew's beads of courage as a symbolic representation of his journey through cancer treatment, and Jack's journey alongside him.....   | 61  |
| Figure 4. A photograph showing Max's daughter Hillary's beads of courage, which is a symbolic representation of Hillary's journey through child cancer, and Max's journey alongside her. A bead in the form of a face, signifying hair loss, can be seen in the top central region of the photograph ..... | 62  |
| Figure 5. A photograph showing empty containers of oral medication, as an illustration of James' practical role in managing his daughter Jessica's medication .....  | 64  |
| Figure 6. A photograph showing a portacath and box of hospital bands belonging to Dan's daughter Charlotte .....   | 68  |
| Figure 7. A photograph showing James' daughter Jessica's beads of courage as a representation of her bravery during injections (represented by black beads). ....  | 77  |
| Figure 8. A photograph showing a poster made for Luke's son Ryan as a sign of support from his pre-school.....   | 80  |
| Figure 9. A photograph showing a mug signed by David Tua and given to Jack's son Matthew as a sign of support .....  | 81  |
| Figure 10. A photograph showing a packet of cheese balls and a carton of eggs, the main foods eaten by Dan's daughter Charlotte during stays in hospital.....  | 103 |
| Figure 11. A photograph showing Max's daughter Hillary's favourite toy, a polar bear which comforted her during medical procedures .....   | 104 |
| Figure 12. A photograph showing the mask that David's daughter Rachel wore during radiation treatment.....   | 110 |
| Figure 13. A photograph showing the regimental beret that Jack gave to his son Matthew in recognition of the courage he displayed during his cancer treatment .....  | 111 |

# Chapter 1

## Introduction

This chapter provides an introduction to the thesis, scope of the research, and main research questions and aims. The topic of childhood cancer is explored to provide an important background and context to the research, and literature in the area of childhood cancer is reviewed. The importance of exploring the experiences of fathers of children with cancer is discussed, and discourses around fatherhood and masculinity that may be relevant to the experiences of fathers of children with cancer are considered.

### **Introduction to the Thesis**

“Your child has cancer.” Those four terrifying words mark for many parents the beginning of an uncertain and challenging journey through their child’s diagnosis and treatment for childhood cancer.

A diagnosis of childhood cancer can be a life-changing event for both the child and their entire family (McCubbin, Balling, Possin, Friedrich, & Byrne, 2002). Despite notable medical advancements and an increase in paediatric cancer survival rates (Greenlee, Murray, Bolden, & Wingo, 2000; McCubbin et al., 2002), cancer is still the second most common cause of childhood mortality (Ward, 2000). A child with cancer and their family may face the challenge of an uncertain future (Hilden, Himmelstein, & Freyer, 2001; McGrath, 2002; Sanatacroce, 2002), as well as negotiating aggressive treatments and distressing symptomatology (Schneider, 1999).

Childhood cancer is synonymous with change: each family member is affected by their own experience of the disease as well as changes to family life and family relationships. A family systems view proposes that the family is a system in which all members have a reciprocal influence on other members of the family (Patterson, Holm, & Gurney, 2004). In this way, a child’s experiences and challenges throughout their cancer journey play an important role in the responses and experiences of their father, mother, and siblings. Likewise, the decisions, experiences, and responses of the father, mother, and siblings may have reciprocal effects and significant implications for the child. It is evident that the experience of a cancer diagnosis and the treatment that

follows is not isolated to the child it pertains to, but instead is an experience which is shared by the whole family.

My personal experience as member of a family affected by cancer inspired this research topic. As the adolescent daughter of a mother diagnosed with breast cancer, I observed and later reflected on the significant impact that the journey through treatment had not only on my mother, but on my father, my twin sister, my brother, and myself. We shared the experience as a family yet we all responded differently. As a daughter, it was hard to see my mother, a woman I respected as a pillar of strength and certainty and a parent I had looked up to my whole life, undergoing significant physical and emotional distress throughout her treatment. That experience changed me profoundly, and sparked my interest in the impact that cancer can have on the family.

In the search for a focus to this topic, I decided to look at how the experience of cancer might play out when the dynamics of the parent-child relationship were the reverse of my own experiences – when the child was diagnosed with cancer, rather than the parent. This focus was directed by an interest in how a child's diagnosis with cancer might have a profound impact on their mother or father. My own experiences were shaped by the realisation as a teenager that the roles had now reversed – my mother was now the vulnerable one, and I needed to look after her. I then wondered how a parent, who might identify strongly with the need to care for and protect their child, might experience the realisation of their child's vulnerability and their own feelings of helplessness in protecting them from the hardships of treatment.

Research suggests that parents of children with cancer may experience significant emotional, financial, social, and physical challenges during the often lengthy process of treatment (Dockerty, Skegg, & Williams, 2003; Vannatta & Gerhardt, 2003; von Essen, Sjoden, & Mattsson, 2004; Wallander, Thompson, & Alrikson-Schmidt, 2003). As the head of the family unit, parents may need to coach their child through painful treatments, negotiate changes in the parent-child and sibling relationships, and manage role and occupational changes (McCubbin et al., 2002). Studies also suggest that mothers and fathers may react to and experience childhood cancer in differing ways (Clarke, McCarthy, Downie, Ashley, & Anderson, 2009).

While a greater understanding of mothers' experiences of childhood cancer would have also been valuable, I chose to narrow the focus of my research to fathers. As suggested by May (1996), fathers have in many ways become the 'forgotten parent'. In examining the current literature, it became apparent that there was a relative

paucity of studies focused on fathers of children with cancer, in comparison to mothers. This seemed to be a consequence, in part, of the assumption that mothers traditionally are more likely to take on the role of primary caregiver, to look after their child while in hospital, and would be more available and willing to engage as research participants. In directing my thesis toward a focus on fathers of children with cancer, I wanted not only to contribute to an area where research was currently lacking but also to challenge the reasons that fathers have been overlooked as valuable research participants in the past. I sought to explore fathers' experiences of caregiving and active involvement in their child's care, the trials and triumphs of fatherhood during childhood cancer, and the discourses of fatherhood and masculinity that shaped expectations of roles and responsibilities during the crisis of cancer.

My goal was to listen to fathers' stories, to delve deeply into the meaning embodied within those stories, and to then share those stories. As such, following a narrative pathway for my research was a logical choice. I would ask fathers to share stories of their experiences during their child's cancer, and then through this thesis, tell my story of learning and discovery as I investigated fathers' stories.

It seemed timely to ask these fathers to tell their stories, as in many ways, society seems to be moving toward a more equal distribution of caregiving and breadwinning roles among mothers and fathers, and yet many traditional assumptions about masculinity and fatherhood seem to be firmly entrenched. For example, in recent decades there has been a notable increase in caregiving duties undertaken by the father (Coltrane, 1995), and in the number of fathers acting as the primary caregiver for their children (Statistics New Zealand, 2013). However, the ideal of the 'kiwi bloke' who drinks beer, plays rugby, provides for his family, and does not show his emotions (Phillips, 1987), is still very much prevalent in society (Lee & Owens, 2002). In the context of childhood cancer, when it is likely that emotions are running high, I wanted to investigate how fathers experienced and navigated their own masculinity and fatherhood, and to ensure that their stories were not forgotten.

The following sections establish a foundation for my research, through a review of literature regarding childhood cancer and its impact on the family. Taking a critical look at what past research about childhood cancer tells us is important because the authors have had an influential voice in constructing the ways in which childhood cancer is understood, shaping societal attitudes towards families of children with cancer, and in informing social policies, information, service provision, and practices.

These in turn shape families', and in particular fathers', experiences of childhood cancer.

### **Childhood Cancer**

Childhood cancer can be a particularly intrusive and intense chronic illness for the entire family unit to manage. The term 'paediatric cancer' encompasses a wide range of malignant diseases, each with its own epidemiologic and biological characteristics, treatment strategies, and survival rates (Pizzo & Poplack, 2002). However, most childhood cancers have in common that the associated treatment can be lengthy, dangerous, and painful (Patterson et al., 2004). An estimated 175,000 children aged 15 years and younger are diagnosed with paediatric cancer worldwide each year (American Cancer Society, 2011), while in New Zealand the number of children diagnosed annually is about 115 (Ministry of Health, 2013). In New Zealand, child cancers are most commonly leukaemias (about 40%), followed by brain tumours (about 25%), while the remainder is largely comprised of other germ cell tumours (Blakely et al., 2010).

After a medical diagnosis of childhood cancer has been confirmed, an individual treatment plan is formulated for a child with cancer. This most commonly includes one or any combination of three major oncology treatments: surgery, radiation therapy, and chemotherapy (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). Surgery usually involves an invasive procedure in which a tumour is removed, while radiation therapy involves the localised use of a high-energy radiation to eliminate cancer cells and to keep them from reproducing (Cancer Society of New Zealand, 2009). Finally, chemotherapy is the use of anti-cancer drugs to kill cancer cells and stop them from dividing and multiplying (Cancer Society of New Zealand, 2012).

It is common for a patient to experience a number of side effects such as pain, hair loss, nausea, vomiting, anticipatory anxiety, and fatigue as a result of cancer treatments (Enskar, Carlsson, Golsater, Hamrin, & Kreuger, 1997; Hogan, 1997), which may be particularly distressing for the child and their family. While there is a substantial amount of literature focused on the medical processes of treatment for childhood cancer, studies that focus purely on the medical or biological aspects such as side effects or treatment outcomes are unable to capture the full richness of lived experience – the emotional, psychosocial, and personal components of what it means for a child to undergo treatment, and for a family to journey alongside them. Accordingly, this review of the literature will outline medical aspects of treatment in

order to provide a clear understanding of the process of child cancer treatment, and will then focus predominantly on studies exploring how children and their families experience childhood cancer and its treatment, and the impact it may have on them across many domains of life.

It is common for children with cancer to undergo invasive medical procedures and to endure hospitalisation for long periods of time (Taleghani, Fathizadeh, & Naseri, 2012). While cancer treatments such as surgery, radiation therapy, and chemotherapy can be effective in halting tumour growth, minimising cancer-related pain, and extending life for children with cancer, they can also produce substantial side effects (Lipscomb, Gotay, & Snyder, 2007). These side effects may be short-term and limited, or long-term and persistent, and can manifest during treatment, or even emerge years later (Lipscomb et al., 2007). Long-term effects of treatment for childhood cancer vary and have been reported to include problems such as neurocognitive deficits (Butler & Mulhern, 2005; Packer et al., 2003), reduced growth, damage to organs, increased incidence of illness, endocrine or cardiovascular conditions (Gleeson, Darzy, & Shalet, 2002; Gurney et al., 2003), infertility (Green et al., 2009), and chronic or life-threatening diseases (Oeffinger et al., 2006).

Cancer and treatment-related symptoms can add to the sense of suffering and helplessness felt by children and their families (Kane & Primomo, 2001). A study by Hedström, Haglund, Skolin, & Von Essen (2003) investigated how children and adolescents with cancer might experience not only physical but emotional distress, as a result of cancer treatment. They found that children were most likely to describe pain from medical procedures as physically distressing; while feelings of confinement, alienation, and worry about death, were described as emotionally distressing. Hedström et al. (2003) also found that children under seven years old were more likely to report physical experiences as distressing, while children aged eight to twelve more commonly described emotional events as distressing. This study suggests that older children, at a later developmental stage, may be more focused on and aware of the emotional impact of the cancer treatment, while younger children may be more distressed by immediate events involving unpleasant physical sensations and discomfort. This study is important in highlighting how children may experience treatment as distressing in a number of different ways, due to factors such as their developmental stage and emotional maturity, and affirms the idea that a child's experience of cancer should not be reduced to a list of symptoms, side effects, and outcomes.

Research has further suggested that cancer symptoms, side-effects, and the physical demands of treatment can affect children's social and psychological functioning. Childhood cancer has been reported to cause considerable discomfort and significantly impact a child's developmental milestones, quality of life, and their psychological, social, emotional, and spiritual wellbeing (Barrera et al., 2004). However, conflicting findings have been reported in the literature regarding the psychological and social adjustment of children with cancer. While some children seem to cope well with the shock of diagnosis and beginning of treatment, a small but significant subset of children experience psychological difficulties such as depression, anxiety, and social withdrawal (Friedman & Meadows, 2002; Wintgens, Boileau, & Robaey, 1997).

A number of studies have reported adverse effects that may be present in childhood cancer survivors, as a result of their treatment experiences (Barrera et al., 2004). In the long-term, survivors may show lower rates of academic success than their peers (Haupt et al., 1992; Katz, Rubinstein, Hubert, & Blew, 1988) and may be more likely to experience employment difficulties (Hays et al., 1997; Zeltzer et al., 1997). Studies have also suggested that some childhood cancer survivors may experience impaired social relationships (Mackie, Hill, Kiomdryn, & McNally, 2000; Mulhern, Wasserman, Friedman, & Fairclough, 1989) and an altered sense of self or lower self-esteem (Greenberg, Kazak, & Meadows, 1989; Madan-Swain et al., 2000). Children have also been reported to have experienced impaired personal (Mulhern et al., 1989; Smith & Ries, 1991) and familial functioning (Kazak et al., 2001; Kupst & Schulman, 1988) during cancer treatment.

Conversely, a number of studies have suggested that there is no psychopathology present in cancer patients and survivors (Kazak, 1994; Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993; Noll et al., 1997) and little difference between the psychological functioning of children with cancer and healthy controls (Eiser, Hill, & Vance, 2000; Noll et al., 1993; Patenaude & Kupst, 2005). Survivors of childhood cancer also reported less anxiety and depressive symptoms than their peers (Canning, Canning, & Boyce, 1992; Phipps & Srivastava, 1997). It seems evident from the discrepancy between these two groups of studies that children may respond to the experience of cancer in a variety of ways. Their experiences may be too complex to be reduced to a simple categorisation of coping well or not coping well, based on a chosen set of outcomes. One critique of the approach taken by the majority of the above studies is that they should focus on the differences in experience and outcome for children with cancer, rather than aggregating children with cancer and comparing them



to children without cancer. Perhaps more research needs to be directed into exploring in greater depth the unique ways in which children with cancer respond socially and psychologically to treatment, rather than comparing them to children without cancer by using a preset list of outcomes.

Studies in this area have also tended to focus on the negative psychosocial outcomes that children may experience as a result of cancer treatment, and have largely neglected to acknowledge any positive experiences or outcomes that may occur. The small number of studies which have explored this possibility suggest that children with a history of childhood cancer may experience a number of positive outcomes, such as greater resilience, a positive re-evaluation of priorities, and a greater appreciation of loved ones and life following cancer treatment (Eiser et al., 2000; Patenaude & Kupst, 2005; Zebrack, Chesler, Orbuch, & Parry, 2002). Elkin, Phipps, Mulhern, and Fairclough (1997) investigated the psychological functioning of 161 young adult survivors of childhood cancer and reported significantly better psychological health and lower levels of distress than healthy comparisons. Similarly, childhood cancer survivors have been reported to have lower levels of substance abuse, as well as less antisocial behaviour and aggression than normative controls (Verill, Schafer, Vannatta, & Noll, 2000). Research in this area has also tended to focus on comparisons with healthy controls, rather than delving deeper into an exploration of the heterogeneity of children's responses to and experiences of cancer and why some children may experience positive outcomes.

Every cancer experience is unique – not all children are able to learn to cope with cancer-related stressors and time does not always bring an improvement in adjustment. Research has suggested that a child's response to and journey through cancer treatment may be influenced by previous experiences, level of parental adjustment, temperament, age, developmental maturity, perceived control, and level of social support (Patenaude & Kupst, 2005; Zeltzer, 1994). Although the impact of age differences on a child's adjustment to cancer is not well understood, studies have suggested that their age and developmental level may influence the ways in which cancer-related problems manifest in that child (Kazak, 1994; Sawyer et al., 1995). The first five years of a child's life are seen as crucial for social development and researchers have argued that children with cancer in this age bracket may be at particular risk for psychological maladjustment (Parker & Asher, 1987; Spirito et al., 1990). Younger children may also have greater difficulty understanding their illness and the need for painful treatment procedures in comparison to older children (Barrera, 2000). Similarly, research has suggested that younger children may cope less well with



extended hospitalisation and be more expressive of distress than their older counterparts (Barrera, 2000). However, older children and adolescents may experience additional challenges because of their age, increased cognitive abilities, and emotional awareness (Barrera et al., 2004). Older children and adolescents are often more aware of the implications of the cancer and treatment, and may therefore struggle with disruptions to the attainment of developmental milestones, such as autonomy and identity (Kazak, 1994; Madan-Swain et al., 2000).

Research has also found that temperament may have an important role to play in a child's psychological adjustment to childhood cancer. Thomas and Chess (1977) propose that a child's temperament, or characteristics and patterns of behaviour, can interact with the environment to produce an action or response. Temperament dimensions such as persistence, activity, mood and distractibility have been linked to pain reports from children with cancer (Broome, Rehwaldt, & Fogg, 1998). Researchers have argued that these differences in temperament may represent increased vulnerability to stressful events in some children (Sawyer, Steiner, Antoniou, Toogood, & Rice, 1998). Overall, it seems evident that there are a number of variables that influence a child's response to cancer, which may explain discrepancies in studies showing that some children experience adverse effects as a result of cancer, while other children show resilience.

In summary, a review of the literature suggests that a diagnosis of cancer and the treatment that follows are significant and traumatic events that can impact a child across physical, psychosocial, emotional, developmental, and behavioural domains. Research has indicated that children with cancer may also suffer from short- and long-term effects such as physical problems (Hudson et al., 2003; Lipscomb et al., 2007), impaired psychosocial functioning (Boman & Bodegard, 1995), and externalising behaviour problems (Barrera et al., 2003). The extent of the impact across each of these areas can be influenced by factors such as temperament, internal resources, family cohesion, developmental maturity, previous experiences, parental adjustment, and social support.

These variables are useful as a starting point in helping us to understand which individual factors may contribute to a child's psychosocial adjustment to cancer. However, it is also important not to underestimate the impact of broader factors such as family response and social support. Studies focusing on individual factors, as a means of predicting adjustment to childhood cancer, make the assumption that factors specific to the child can be studied in isolation from the family. Viewing the child as a separate entity from their family reflects values of a Western, individualistic culture, and

does not take into account systemic theories about family, or the fundamental importance of family in more collectivist cultures. For example, in the Māori culture, the concept of whānau (family) is central to a person's identity, sense of belonging, parenting practices, and wellbeing, and is a network that extends well beyond the nuclear family unit (Durie, 1994).

### **Childhood Cancer and the Family**

A childhood cancer diagnosis inevitably brings changes for the entire family unit, and not just the child. In turn, the way in which a family adjusts and adapts to these challenges can have a significant influence on the affected child's experiences and quality of life. While I would like to acknowledge that for many people and cultures, the term family encompasses more than the nuclear family, and that extended family members can play a very important role following a diagnosis of childhood cancer, most research in this area has been carried out by Western researchers in Western settings with a focus on nuclear families. Therefore, it follows that this review of childhood cancer and the family will also focus predominantly on immediate family members – fathers, mothers, and siblings of the child with cancer.

A family systems view emphasises a reciprocal sequence of effects, where what happens to one family member, in this case the child, affects the others (Patterson et al., 2004). Likewise, how each family member responds to adverse events has a reciprocal influence on the affected child's responses and functioning (Brown et al., 1993; Patterson & Garwick, 1994). In support of this, correlations between a child's psychosocial maladjustment and their parents' psychopathology have been reported (Brown et al., 1993), as well as child-parent links to post-traumatic stress disorder symptoms, in survivors of childhood cancer (Barakat et al., 1997; Kazak et al., 1997). These links suggest that family members are part of an inter-connected system in which maladaptive coping responses from one member can have an adverse affect on other members' adjustment to treatment, although it is important to note that no causal claims have been made.

Family responses may also be positive and protective, and can help to buffer family members from negative psychosocial outcomes (Patterson & Garwick, 1994). For example, effective parental adjustment and coping can help to minimise feelings of hopelessness in children undergoing treatment for childhood cancer (Blotcky, Raczynski, Gurwitch, & Smith, 1985). Understanding how the positive and negative responses of the family unit may influence children's experiences may aid in a greater

understanding of how the psychosocial wellbeing of the child and other members of the family may be connected, following a cancer diagnosis.

The importance of maintaining a focus on the entire family unit is also supported in McCubbin and McCubbin's (1993) resiliency model of family stress, adjustment, and adaptation. They propose that when a member of the family becomes seriously ill, there is a need to focus on the reactions of the family unit as they progress through the crisis stage to the adjustment and adaptation phases, and strive to achieve a sense of balance within the family system (McCubbin & McCubbin, 1993). A study by Björk, Wiebe, and Hallström (2005) also suggests that the balance of family life is significantly disrupted during the crisis of cancer. Björk et al. (2005) explored the experiences of 17 families following a childhood cancer diagnosis and found that the security of family members' everyday lives fell apart, and that they were left with a 'broken life world', rife with loneliness, fear, and uncertainty about the future. Families began 'striving to survive' and worked together to gain control of the chaos, to instil hope, and to find a positive focus. In this way, families felt as though they were able to reduce feelings of loneliness, strengthen the family unit, and rebuild family life. This study seems to be consistent in a general sense with McCubbin and McCubbin's (1993) model of stress, resiliency, and adaptation, as both emphasise the significance of studying the impact of child cancer on family processes and dynamics, and the need for families to rebuild and restore balance to family life.

Learning to live with childhood cancer can be a significant and challenging transition for families. Clarke-Steffen (1993; 1997) suggested that families may use six major strategies to manage the diagnosis of cancer. First, families may manage the flow of information related to the disease and family members' responses to the cancer, and to disperse this appropriately among family members. Secondly, families may undergo a reorganisation of roles within the family unit and in relation to the community, in order to meet the demands of the cancer treatment. Thirdly, families may re-evaluate their values and priorities. Fourth, families may have a shift in future orientation from long-term to short-term, as they focus more on daily and weekly progress than on distant goals for the affected child's future. A fifth strategy during the transition period is the construction of meaning around the disease's cause and effects. Finally, families may use strategies to manage the treatment process, its side effects, and consequences. Clarke-Steffen (1993; 1997) provides an interesting framework through which to view a family's cancer journey and highlights some of the myriad of stresses and challenges faced by families during this difficult time. His findings may be helpful in providing an overall understanding of some of the strategies and transitions

families might go through while navigating their way through childhood cancer; however, simplifying families' methods of adjustment into six key strategies may be overly simplistic as different family members may choose to use strategies in differing ways, during different stages of treatment.

It is evident that a childhood cancer diagnosis can have a tremendous impact on the family and that they may face a number of changes and challenges at each stage of the cancer journey. The child with cancer, as well as their siblings, mother, and father, must each come to terms with the cancer diagnosis and the impact this will have on their daily lives. Having established an awareness of the reciprocal effects that may occur within a family following a child's cancer diagnosis, it is important to explore in greater depth the experiences of siblings, mothers, and fathers of children with cancer.

### **Siblings' experiences of childhood cancer**

Childhood cancer can have a significant impact on the lives and experiences of the siblings of the affected child. Research has suggested that siblings will experience changes in family functioning, disruptions to family routines, and the emotional strain of a seriously unwell brother or sister (O'Brien, Duffy, & Nicholl, 2009). Knowledge around sibling reactions and experiences, following a brother's or sister's diagnosis with cancer, is important as it can contribute to an overall understanding of family functioning, and furthermore, provide understanding into the how other members of the family, such as parents, respond to siblings throughout the cancer journey.

A recent systematic review (Alderfer et al., 2010) investigated literature on the psychosocial adjustment of siblings of children with cancer and argued that a significant subset of siblings experience negative emotional reactions, symptoms consistent with post-traumatic stress, and reduced familial, social, and emotional quality of life. Alderfer et al.'s (2010) review also indicated that effects can be both short-term, with the highest levels of stress experienced by siblings tending to be around the time of diagnosis, and long-term, where siblings may exhibit difficulties at school even at two years following diagnosis. A literature review by O'Brien et al. (2009) similarly reported that siblings may experience difficulties with emotional adjustment and peer interactions. In particular, sisters of children with cancer were suggested to be more at risk of depressive and anxious symptoms than brothers, perhaps due to an increased expectation or tendency to take on household responsibilities, and a burden of caring for their ill sibling (Houtzager, Grootenhuis, Hoekstra-Weebers, & Last, 2005; O'Brien et al., 2009). These findings suggest that

having a brother or a sister with cancer may be associated with difficulties across a number of domains of life.

Living with a brother or sister with cancer can be a distressing experience for siblings, with emotions such as anger, loneliness, guilt, isolation, anxiety, depression, displacement, and deprivation reported (Haverman & Eiser, 1994; Houtzager, Grootenhuis, & Last, 2001). Some studies have reported few differences between siblings of children with cancer and control groups (Evans, Stevens, Cushway, & Houghton, 1992; Horwitz & Kazak, 1990); however, a number of other studies have reported a greater likelihood of behaviour problems, academic difficulties, poor social relationships, and mood problems for siblings of children with cancer (Hefferman & Zanelli, 1997; Phuphaibul & Muensa, 1999; Sloper & While, 1996).

While the above studies have been helpful in providing an indication of some of the emotions and difficulties siblings of children with cancer may experience, it is also important to look deeper and to question what is behind the internalising and externalising behaviours that have been reported. Studies suggest that siblings may report a sense of loss of normal family life and an overshadowing of their identity within the family (Alderfer et al., 2010; Woodgate, 2006b). Siblings have also shared stories of change, enduring sadness, and unmet needs (Wilkins & Woodgate, 2005; Woodgate, 2006b). These studies suggest that siblings may feel disconnected or unsure of their place within the family, following a brother or sister's diagnosis with cancer. These feelings of isolation and the frustration of unmet needs, in turn, may lead to mood or behavioural problems. Other researchers have also suggested that behavioural problems may often mask feelings of isolation and resentment (Hamama, Ronen, & Feigin, 2000; O'Brien et al., 2009).

As with research relating to children with cancer, most research on siblings of children with cancer tends to focus on negative experiences or outcomes. This has the effect of positioning siblings as victims of their brother's or sister's cancer, rather than acknowledging them as members of the family that have the potential to be resilient, helpful, and supportive. Research that has focused on positive outcomes has reported that siblings of children with cancer may show increased maturity, empathy, and commitment to keeping the family together through difficult times (Alderfer et al., 2010; Haverman & Eiser, 1994; Woodgate, 2006b). Although siblings face a number of challenges and difficulties during their brother or sister's cancer treatment, it appears that the greater responsibility and independence that siblings may experience during this time may be a catalyst for increased maturity and empathy in some siblings.

Much like the ill children themselves, the ways in which siblings react to the changes and challenges of a brother's or sister's cancer can differ depending on a number of factors such as family characteristics, available resources, supports, and personal strategies for coping (O'Brien et al., 2009). Barrera et al. (2004) indicated that social support may play an important role in psychosocial adjustment: siblings who reported higher levels of social support experienced less depression, anxiety, and behavioural problems. Labay and Walco (2004) explored empathy and psychosocial adjustment in siblings of children with cancer and reported two primary findings. First, they reported that siblings with higher levels of empathy presented with less adjustment difficulties than siblings with lower levels of empathy (Labay & Walco, 2004). Secondly, Labay and Walco (2004) suggested that siblings from larger families have increased vulnerability compared to siblings from smaller families, and highlighted the importance of providing support for the entire family unit. The researchers suggested that in larger families, emotional and material stresses may be exemplified, making it difficult to meet the needs of individual siblings (Labay & Walco, 2004). Studies (Hamama et al., 2000; O'Brien et al., 2009) have also suggested that the presence of self-control and self-efficacy may be protective factors for siblings of children with cancer.

In summary, the cancer diagnosis and subsequent treatment of a brother or sister appears to be a difficult and challenging time for most siblings. In particular, siblings may struggle with emotional adjustment, role changes within the family, and interactions with their peers (O'Brien et al., 2009). Understanding the struggles that siblings may have contributes to the bigger picture of family adjustment to childhood cancer and may also lend insight into what may be experienced as additional challenges by those managing the family through the crisis – the parents.

### **Parents' experiences of childhood cancer**

As heads of the family unit, the parents of a child with cancer can experience a number of specific stressors and additional responsibilities relating to the diagnosis and subsequent treatment of their child. Following diagnosis, parents need to adjust to the changes in family life, caregiving challenges, and the uncertainty of their child's future. In addition, studies suggest that parents need to be flexible enough to adapt to changing symptomatology, new challenges and complications which arise, and the emotional needs of the child and family (Gibbins, Steinhardt, & Beinart, 2012; Yeh, 2003).



Chesler and Barbarin (1986) propose five major categories of stress experienced by parents throughout their child's cancer process: informational, practical, emotional, interpersonal or social, and existential or spiritual stress. Informational stress encompasses uncertainty regarding the origin or future course of the childhood cancer. Practical stress describes the struggle to handle work, family, household and other responsibilities, as well as daily living. Emotional stress encompasses the experience of guilt, anticipatory loss, helplessness, terror, and other emotions. Interpersonal stress describes challenges related to communication and the preservation of relationships. Finally, it is suggested that parents grapple with existential or spiritual stress – they must adjust to new patterns of family functioning, attempt to create meaning out of what has happened, to rethink priorities and career paths, and reconnect to spiritual beliefs. This classification of concerns into categories of stressors tends to psychologise experience and may simplify the experience that parents go through. Parents are likely to experience these feelings and challenges differently at different stages of treatment, as well as differently throughout the same day. However, while this approach does not document the complexity of the struggles and challenges that parents go through, it does contribute to a broad awareness that parents experience a myriad of stressors and challenges across a number of domains.

The diagnosis of childhood cancer has been argued to have a considerable impact on the psychological wellbeing of the sick child's parents (Pai et al., 2007). The presence of depressive symptoms and psychological distress have been described in studies on parents of children with cancer at diagnosis (Pai et al., 2007), three months (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1999), six months, and twelve months after diagnosis (Dahlquist et al., 1993; Sloper, 2000; Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006). In a follow-up five years after diagnosis, Wijnberg-Williams et al. (2006) reported that a substantial number of parents continued to suffer from psychological distress, although overall distress levels of parents decreased over time. Post-traumatic stress symptoms have also been reported by parents during their child's treatment: in a study by Kazak, Boeving, Adlerfer, Hwang and Reilly (2005) only one parent in a sample of 171 was assessed to be without post-traumatic stress symptoms. An earlier study by Kazak et al. (1997) indicated that post-traumatic stress symptoms were also commonly present in parents of cancer survivors several years after treatment had finished. While these studies are helpful in indicating the extent of psychological distress that some parents may experience, measuring psychological distress via lists of symptoms associated with mental disorders may pathologise what may merely be an understandable reaction to the shock of diagnosis, the subsequent

flood of emotions, and the stress of lifestyle changes resulting from the cancer treatment.

Several studies have indicated that a child's diagnosis with cancer may contribute to their parents' marital strain: a study by Yeh (2002) reported greater marital dissatisfaction for parents who were within two months of the original diagnosis. That these difficulties may be, in part, due to parents experiencing shock at the cancer diagnosis and struggling to adjust to the demands of treatment and changes in family life, is consistent with the result of other studies indicating adjustment difficulties for parents of children with cancer (Rocha-Garcia et al., 2003; Taleghani et al., 2012; Yeh, 2002; Yin & Twinn, 2004).

However, some researchers have argued that parents are able to adjust adequately to their child's diagnosis and treatment for childhood cancer (Barrera et al., 2004; Birenbaum, 1990). A study by Brown et al. (1993) reported comparative levels of psychological adjustment in parents of children with cancer, relative to a control group. Improvements in parental adjustment to an adequate level of functioning were also reported one or two years after diagnosis, in those who were initially struggling to adjust (Madan-Swain et al., 2000). Furthermore, some studies have indicated positive changes for parents and families following diagnosis and during treatment for childhood cancer. A study by Rocha-Garcia et al. (2003) suggested that the most common emotional response to a diagnosis of leukemia was the strengthening of family bonds. Other studies focusing on the experiences of families of children with cancer have also described increased family cohesion, a positive shift in life perspectives, and personal growth (Chesler, Allesewede, & Barbarin, 1991; Sloper, 2000; Van Dongen-Melman, Van Zuuren, & Verhulst, 1998). Discrepancies between studies suggesting that parents struggle to adjust to their child's cancer and those which report adequate adjustment may be in part due to the diversity of parents' experiences, differences in the severity of cancer diagnoses, and individual personality variables. More research focused on the heterogeneity of coping experiences across a range of parents may be able to shed some additional light on the complexity of parents' experiences and process of adjustment relating to their child's cancer.

The experiences and responses of parents during childhood cancer is a crucial topic for research, not only because of the psychological impact that a child's cancer may have on the parents, but also because of the far-reaching effects the parents' psychological wellbeing can have on the entire family unit (Wilkins & Woodgate, 2005). Sanger, Copeland, and Davidson (1991) reported that a child's degree of adjustment to a diagnosis of paediatric cancer was associated with parental coping. Wolfe-



Christensen et al. (2010) alternatively indicated that parental stress may be a predictor of children's behavioural, emotional, and social adjustment to their cancer. Hill et al. (2003) and Trask et al. (2003) also highlighted the important role that mothers, fathers, and cohesive family support play in a child's psychosocial coping and adaptation. Furthermore, sibling wellbeing is strongly linked to the fulfilment of crucial needs by parents such as parent-sibling communication, parental involvement, emotional availability, and support to maintain a sense of self through their own interests and activities (Murray, 2002; Wilkins & Woodgate, 2005). These studies strongly suggest that there is a relationship between parents' responses to their child's diagnosis with cancer and the psychosocial adjustment of the child and other siblings.

Parents have a significant place of leadership and responsibility within the family unit and it seems important therefore to pursue a more in-depth and detailed understanding of the experiences of mothers and fathers during childhood cancer, not only to provide adequate support for the parents themselves, but also to provide holistic care for the entire family.

### **Mothers' experiences of childhood cancer**

The majority of past research has focused on maternal, rather than paternal, experiences of childhood cancer (Shudy et al., 2006). This is partly because mothers are more likely to take on the role of primary caregiver of their sick child (Zebrack et al., 2002), and therefore are perceived to be more knowledgeable informants for research related to child cancer (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). In addition, mothers have historically been more available and willing to participate in scientific research, as illustrated by a dominance of mothers participating in childhood cancer studies looking at both parents (e.g. Dixon-Woods, Findlay, Young, Cox, & Heney, 2001; McGrath, 2001; Yin & Twinn, 2004).

Studies have indicated that a child's diagnosis with cancer may have a number of adverse implications for their mother. Young, Dixon-Woods, Findlay, and Heney (2002) conducted semi-structured interviews with 20 mothers of children with cancer and reported that mothers experienced a disrupted sense of self and social identity following their child's diagnosis. Young et al. (2002) also described the enormous physical and emotional burden that was felt by mothers as they were pressured to take on new responsibilities, to remain close to their child to provide care and comfort, and to fulfil increased role expectations. Overall, they concluded that quality of life suffered in many ways for mothers of children with cancer. Similarly, a study comparing mothers

of children with leukemia to mothers of healthy children reported a reduced quality of life for mothers of children with cancer, particularly in the areas of mental health and social functioning (Yamazaki, Sokejima, Mizoue, Eboshida, & Fukuhara, 2005). Research has also reported the presence of post-traumatic stress symptoms in a substantial proportion of mothers of children with cancer (Manne, DuHamel, Gallelli, Sorgen, & Redd, 1998; Pelcovitz et al., 1996). These symptoms have been suggested to be linked to long-term adjustment issues (Barakat, Kazak, Gallagher, Meeske, & Stuber, 2000).

Furthermore, mothers have reported struggling across cognitive, emotional and physical domains. Challenges around support, accessing the health care system, family dynamics, and future plans have been identified as major sources of worry for mothers of children with cancer (Ward-Smith, Kirk, Hetherington, & Hubble, 2005), while mothers have also described experiencing increased emotional sensitivity, nervousness, and irritability (Elcigil & Conk, 2010). In addition, somatic symptoms such as insomnia, headaches, decreased appetite, and back pain have also been described by mothers of children with cancer. It seems evident that mothers often experience their child's diagnosis and treatment for cancer as distressing across a number of different domains.

Mothers may also experience role strain while caring for a child with cancer. Demands of proximity to the sick child and a sense of responsibility to meet their needs led some mothers to report feelings of isolation, and a change in their sense of identity as a mother (Fletcher & Clarke, 2003). Mothers reported struggling to maintain or feel competent in previous roles such as wife, mother to healthy children, and employee (Clarke, 2006; Kars, Duijnste, Pool, van Delden, & Grypdonck, 2008). The internalisation of experiences has been reported by a number of mothers, with many describing having kept a personal journal as a helpful coping strategy (Johns et al., 2009). Mothers often play a vital role in their child's journey through cancer and it is important to have a growing awareness of their experiences and challenges relating to motherhood, and the impact that these may have on a mother's wellbeing.

The psychological wellbeing of mothers is also important because of the reciprocal effects it can have on the quality of life of children with cancer. Two reviews have argued that maternal psychosocial adjustment may impact directly on children's psychosocial adjustment (Drotar, 1997; Lavigne & Faier-Routman, 1993). This relationship has been supported in the context of childhood chronic illness (Thompson & Gustafson, 1996) and paediatric cancer (Barrera et al., 2003). Furthermore, Sawyer et al. (1998) reported an association between maternal adjustment to childhood cancer

and children's adjustment two years following diagnosis with cancer, and Ritchie (2001) described mothers as one of two primary sources of support for adolescents with cancer.

As a parent, mothers can carry a significant portion of the family burden and responsibilities following a child's diagnosis with cancer. It seems evident that the added stressors and worries of adjusting to a child's diagnosis with cancer, and the changes in family life that cancer treatment can bring, have the potential to significantly impact mothers' wellbeing. For this reason, as well as the proposed link between maternal and child adjustment, it seems important to support the mother, as well as the ill child, following a cancer diagnosis.

### **Fathers' experiences of childhood cancer**

Fathers also play an important role and may therefore have crucial influence on the sick child and family's psychosocial functioning following the diagnosis of childhood cancer. There have, however, been relatively few studies investigating the experiences of fathers or the differences in responses that mothers and fathers may have to their child's cancer journey (Phares et al., 2005). The few studies that have been conducted in this area suggest that fathers may have different responses, experiences, and understandings of their child's cancer in comparison to mothers (Clarke-Steffen, 1997).

Fathers and mothers sometimes exhibit different coping styles in response to their child's cancer diagnosis. Reay, Bignold, Ball, and Cribb (1998) used in-depth interviews to explore gender dynamics in families coping with childhood cancer. They suggested that fathers tend to distance themselves emotionally from the cancer, often demonstrating a reluctance to talk, an overly optimistic stance, and minimisation of the impact of the cancer diagnosis (Reay et al., 1998). It has also been reported that fathers are more likely to express psychological struggles in less obvious ways than mothers, and to suppress emotions that they perceive as weak or undesirable (Silver, Westbrook, & Stein, 1998). Studies suggest that fathers tend to demonstrate a more practical coping style, compared with the emotional release exhibited by mothers (Larson, Wittrock, & Sandgren, 1994; Mastroyannopoulou, Stallard, Lewis, & Lenton, 1997) and may focus more directly on their child's diagnosis rather than seeking diversion (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998). These findings were supported in a recent review which reported trends towards greater support-seeking behaviours, emotionally-focused coping, and increased stress for mothers when compared to fathers of children with cancer (Clarke et al., 2009). It can be important for

parents to understand that each other's coping styles may differ, as misunderstandings in this area could lead to marital and family conflict, which in turn may adversely affect the ill child's psychological adjustment to diagnosis and treatment.

Research has suggested that fathers often adopt information-seeking and problem-focused coping styles, which may decrease the informational stress they experience (Cayse, 1994; Cohen, 1993). Stress related to the practical and logistical challenges of childhood cancer treatment has been suggested as one of the foremost types of stresses experienced by fathers on a day-to-day basis, and includes concerns about travel, employment, balancing work, family and child care commitments, and managing resources (McGrath, 2001). Alongside practical stress, Cayse (1994) reported that fathers most frequently worried about their child's health and future. Research has suggested that fathers cope with emotional stress by remaining optimistic whilst taking on a protector role for their family, seeking information about their child's cancer, staying calm and tightly controlling their emotions, and distracting themselves with work and other activities (Jones, Pelletier, Decker, Barczyk, & Dungan, 2010; Reay et al., 1998).

While the above studies have provided a helpful indication of the ways in which fathers cope with their cancer and the strategies they employ, they tend to represent what may be more of a process and a journey as lists of stressors and strategies. Studies such as the ones discussed above promote a linear view of the cancer journey, in which a father comes across a hardship or challenge, applies a strategy, and moves forward. However, I would suggest that the reality of a father's experiences of their child's cancer is a messy and difficult process, in which there are both good days and bad days, and where there is a continual process of learning how to adjust and adapt. In the current study, I endeavour to take a more in-depth, explorative approach that explores multiple facets such as the process of coping for fathers of children with cancer, as a part of an investigation into their stories and experiences.

Research has also tended to focus on additional factors that may aid fathers in adjusting to their child's cancer, such as social support. Studies have indicated that social support is especially important for fathers during their child's cancer (Katz, 2002; Shapiro & Shumaker, 1987). Brody and Simmons (2007) used in-depth interviewing to explore the experiences of fathers when confronted with their child's diagnosis with cancer and reported that support from the extended family, church, and health care professionals was necessary for fathers in order to remain positive, while adapting to their child's illness. Fathers seemed more likely to view their marriage as a positive and primary source of support than mothers (Dahlquist, Czyzewski, & Jones, 1996),

although some studies have reported feelings of isolation and vulnerability due to a perceived emotional overinvestment in the child by the wife (Jones et al., 2010; Neil-Urban & Jones, 2002b). Fathers also indicated that a re-evaluation of life and relationships could be helpful in finding meaning within their cancer experiences (Quin, 2004; Yeh, 2004). It seems evident that positive and supportive relationships may be a buffer for fathers during their child's cancer treatment, and in the current study, I would like to explore how relationships between the father and other family members are strengthened, challenged, or changed throughout the cancer journey, as revealed through the stories that they share.

Childhood cancer can often lead to a polarisation of roles within the family: mothers frequently become primary caregivers of the ill child and fathers may, in turn, be faced with the challenge of juggling involvement with cancer treatment with fulfilment of financial and other responsibilities (Cohen, 1999). In past years the traditional division of parenting duties, where mothers took on caregiving responsibilities and fathers provided financially for the family, was reflected in the literature by studies that tended to focus predominantly on mothers' experiences (Dockerty, Williams, McGee, & Skegg, 2000), or showed significant under-representation of fathers as participants when looking at the experiences of both parents (Liaschenko & Underwood, 2001; Seagull, 2000). As the number of fathers actively involved in their children's care (Coltrane, 1995), and in taking on the role of primary caregiver, have increased in recent years (Statistics New Zealand, 2013), there is a clear need for more up-to-date research, such as the current study, to explore the experiences of fathers in today's society.

Another benefit of researching the fathers' perspective is that it may provide a more complete picture of family functioning during childhood cancer, as fathers often play a crucial role in their child's emotional wellbeing and in the stability of the family unit. A recent review (Swallow, Macfadyen, Santacroce, & Lambert, 2011) concluded that fathers' contribution to their child's long-term health care is associated with a positive influence on overall family wellbeing, as well as with fathers', mothers' and children's psychosocial functioning. Robinson, Gerhardt, Vannatta, and Noll (2007) similarly reported a significant relationship between a father's and child's distress in the context of adjustment to childhood cancer, which was moderated by the child's age and gender, family environment, cancer diagnosis, and treatment severity. Quality of involvement by fathers has also been linked to long-term health outcomes for childhood cancer survivors: Hill et al. (2003) conducted a study on the psychosocial functioning of adult survivors of childhood cancer and suggested that lower levels of encouragement

from fathers, were associated with diminished close relationships outside the family, as well as poor psychosocial day-to-day functioning. While these studies provide a helpful indication of a strong link between paternal and child psychosocial functioning, additional research exploring the nuances and complexities of the father-child relationship during childhood cancer may be useful in shedding more light on the dynamics of this relationship.

Overall, it seems evident that fathers play an important role within the family unit during childhood cancer treatment, and that the way they adjust to the diagnosis and additional responsibilities could also have a significant influence on the psychosocial functioning of the child with cancer, and the other members of the family. Literature from the past few decades suggests that fathers may have coping styles and experiences relating to their child's cancer that are different from those expressed by mothers (Jones et al., 2010). Despite this realisation that mothers and fathers may experience their child's cancer journey differently, there is a relative paucity of studies exploring the experiences of fathers of children with cancer. While studies described above have indeed provided some foundational information about the experiences of fathers of children with cancer, further research is needed to investigate the complexity of fathers' experiences, in particular throughout their child's cancer journey.

### **Fatherhood and masculinity**

Father's ideas about fatherhood and roles within their families tend to be strongly influenced by the practices and cultural conceptions of masculinity. Over the past two decades, and particularly in the last few years, there has been a significant increase in gender and family studies exploring how current changes in the idea of fatherhood integrate with social constructions of masculinity (e.g. Doucet, 2006; Marsiglio & Pleck, 2005; Miller, 2011).

Masculinities can be defined as the ideas, characteristics, and cultural conventions related to men's social interactions and practices (Connell, 2005; Hearn, 1996; Pease, 1999). According to Connell (2005), at any time there is one hegemonic masculinity that is perceived to be culturally exalted and the most powerful when illustrating cultural ideals and gendered practices. However, Coles' (2009) theory of the fields of masculinity suggests that there are also other dominant masculinities which describe culturally constructed ideals of a man within a particular field, such as academic masculinity, homosexual masculinity, or paternal masculinity. Each field thus has its dominant constructions of masculinity, which may have some overlap with the



hegemonic masculinity, along with other masculinities which diverge from the dominant one (Coles, 2009).

Masculinity impacts on all aspects of a man's life including fatherhood. While breadwinning has been firmly connected to cultural conceptions of fatherhood since the 20<sup>th</sup> century (Marsiglio, 1993), in more recent decades a diversity of social roles from gender role model to caregiver have emerged in the literature (Eerola & Mykkanen, 2015) and there is an increasing trend towards combining both provider and caregiving roles in the ideals of contemporary fatherhood and masculinity (Roy & Dyson, 2010). This has been encapsulated within the growing ideology of 'involved fatherhood' or the idea that contemporary fathers should be actively involved in the care of their children (Cosson & Graham, 2012; Dempsey & Hewitt, 2012). However, while there are noted changes in ideas about gender, work, and parenting, the extent to which these changes are reflected in actual parenting practice have been debated (Craig, 2006; Featherstone, 2009). Furthermore, several studies (e.g. Palkovitz, 2002; Yarwood, 2011) have suggested that breadwinning continues to be perceived as the contemporary dominant role or duty of fathers. Considerable interest has been also shown in how fathers balance financial obligations with caregiving, and the connection between fatherhood and employment (Brandth, 2012; McDonald & Jeanes, 2012; Miller, 2010).

Fathers' perceptions of what society expects of their role within the family can influence the way they relate as a caregiver and a father. In a study by Chesler and Parry (2001), fathers of children with cancer described acting in accordance with perceived expectations of their role to be strong, suppress their emotions, and provide support for other family members. Although this study was conducted in the United States of America, similar ideas about masculinity are also prevalent in New Zealand (Lee & Owens, 2002). The stereotypical 'kiwi bloke' is rooted in New Zealand's colonial history where pioneering manhood was epitomised by strong, silent men who were rugged and practical, keeping their emotions to themselves (Phillips, 1987). A 'kiwi bloke' is seen as a doer not a thinker, a man who plays rugby, drinks beer, and can be prone to violence (Bannister, 2005). Although these ideals are rooted in New Zealand's colonial history, the idea of the 'kiwi bloke' remains as a dominant discourse of masculinity in New Zealand society. This can lead to tensions between alternative conceptualisations of masculinity as men try to figure out what it means to be a man, and what it means to be a father. With the added physical, emotional, and psychological burdens of journeying alongside their child through cancer treatment, fathers of children with cancer must also work out what it means to be a 'Cancer Dad'.

The experience of fathering a child with cancer is not just about cancer treatment or the child, but it is also about the process of self-discovery, as fathers grapple with what it means to be a father and a man in the context of childhood cancer, and it is this process which I am interested in as part of the current study.

### **Summary and Focus of the Current Study**

In summary, it is important for studies of childhood cancer to focus not only on the ill child but also on the experiences of their family members, as a childhood cancer diagnosis may have a significant impact on each member of the family unit. However, very few studies have focused specifically on the unique issues that fathers face, nor have they explored fathers' perspectives on common challenges throughout a child's cancer treatment. Currently, most research focused on fathers of children with cancer has been quantitative, and does not deal directly with the experience of cancer. The studies discussed above point to some key issues and challenges, such as differences in the ways mothers and fathers respond to their child's cancer, and the ways in which fathers' perceptions of their roles are shaped by traditional conceptualisations of fatherhood and masculinity. Issues and challenges such as these could be investigated in greater depth through the use of qualitative studies, providing a more complex and rich understanding of the experiences of fathers of children with cancer.

In the current study, I explore fathers' experiences during their child's diagnosis and treatment for cancer, in order to discover the meaning embodied within their stories, and to uncover the discourses of fatherhood and masculinity that shaped their experiences during their child's cancer journey. In this way, I hoped to contribute an account of the unique and messy complexity of fatherhood during childhood cancer, to help fathers better understand themselves and each other, and to provide helpful insights that could be used by cancer support services to provide more effective and appropriate supports for fathers and families of children with cancer.



## Chapter Two

### Methodology and Method

This study explores the experiences of fathers of children with cancer from within a qualitative framework, which emphasises the understanding of each personal account and the uniqueness of the individual (Speziale & Carpenter, 2003). Qualitative methods can be particularly suited for psychological research questions, such as those of the current study, which involve exploration and analysis of subjective or constructed meaning (Camic, Rhodes, & Yardley, 2003). This chapter lays the foundations for the current study, which has been positioned within social constructionism and narrative theory, by outlining the theoretical background of social constructionism, and the methodology of narrative theory and analysis. The specific methods employed for the current study are then described and finally, the process of data analysis is discussed.

#### **Theoretical Framework: Social Constructionism**

This study employs a social constructionist approach. Social constructionism is interested in the ways in which social phenomena are constructed: how people go about describing and understanding themselves and their surroundings (Gergen, 1985). The focus is on understanding what is achieved by constructing a phenomenon in a particular way, rather than understanding objectively exactly what a phenomena 'is'.

Social constructionism emphasises the importance of culture and context in the construction of knowledge and an individual's understanding of society. Meaning is constructed by drawing on one's social, cultural, and historical contexts, normative rules (shared understandings in the community), and through interactions among people (Gergen, 1985; Squire, 2000). These influences act firstly on the person telling their story, and secondly on the researcher as they create the research. In this way, language is understood to be a social action and consequently cannot passively or objectively reflect reality in a way that is free from societal values (Gergen, 1985; Gergen, 1999). This complex and multifaceted approach to meaning making is particularly relevant in an exploration of human experience. The purpose of knowledge then is to make clear the processes by which people come to represent their world and to describe common versions of understanding (Gergen, 1985).

There were three main reasons for choosing a social constructionist approach. Firstly, I wanted to explore how fathers of children with cancer chose to shape their narratives and to examine their use of language as a tool in the meaning-making process. Secondly, I wanted to be able to acknowledge the impact of cultural and societal views on fathers' narratives and how perceived expectations about fatherhood and masculinity might influence the way narratives were shared and whether they were deemed acceptable or not. Thirdly, I had an interest in the social construction of a sense of self throughout fathers' accounts of their experiences. I wanted to explore the ways in which fathers' constructed a sense of themselves as a father and as a man, and how this was challenged and shaped throughout the cancer journey.

### **Methodology: Narrative Inquiry**

The construction of narratives is a means by which people make sense of their experiences (Bruner, 1990). Accordingly, narrative inquiry aims to explore the ways in which participants use narratives to understand and create meaning around their lives (Parker, 2005). Narrative inquiry methodology was chosen as it provided the opportunity to go beyond a thematic analysis of the data, and to examine the ways in which fathers used narratives to develop a coherent account of their experiences, position themselves in relation to others, and reconstruct a sense of self through becoming the main character in their own narrative. Narrative methodology also provided an opportunity to look at narratives within their social, cultural, and historical context.

### **What are narratives?**

The term 'narrative' encompasses far more than the term 'story' as it takes into account the purpose, context, and features of the narrative. A narrative has a number of distinctive features: it is an account of events that have occurred, or are expected to occur, and it is coherent, causal, and structured (Denzin, 1989; Murray, 2003). A narrative is a story which constructs a series of past events to give them meaning for the narrator and his or her listener (Denzin, 1989). Narratives are often regarded as the primary means through which human experience and identity are constructed, described, and understood (Linde, 1993; Maitlis, 2012). As such, narratives represent a social construction of the narrator's world, and a way of establishing connections between thoughts, feelings, actions, and events (Gergen, 1999). Therefore, within narrative research, there is no 'correct' narrative or interpretation of an event, as

numerous accounts are possible (Dean, 1998). Events are continually re-scripted in light of new experiences and understandings of the world (Andrews, 2008) and thus narratives provide a window into the narrator's representation of an event at a particular point in time. Interpretations are unavoidable because narratives are personal representations of what happens in the world, and the narrator's agency and imagination determines the plotline and what is emphasised and excluded in the stories they tell (Riessman, 2003).

Narratives are not merely a reflection of experiences in the world, they are constructed, creative, rhetorical, and full of assumptions (Riessman, 2001). Narrative methodology acknowledges that an account of experiences cannot be separated from the context, culture, and language it is created in. Narratives are constrained by societal and cultural structures, as well as an individual's linguistic skills and available resources (Berger & Luckmann, 1967). Within the narrative framework, all stories are assumed to have been shaped by societal and cultural influences (Squire, 2000). Narratives can also be seen to have a dramatic quality: they are comprised of settings, actors, plot, conflict, and resolution (Gergen & Gergen, 1984; Mishler, 1986). Narrators select these narrative features in relation to their own understanding of the event and also how they would like their listeners to understand the event.

Narratives can be useful in creating connections between the ordinary and the extraordinary (McCance, McKenna, & Boore, 2001), and are often formed to explain particular experiences in a person's life where they have experienced a breach between their ideals and reality, or their self and society (Riessman, 1993). In light of this, narratives are particularly relevant in the context of disruptive or life-altering events such as chronic illness, infertility, or divorce, when a person may feel compelled to create meaning as a means of coping with hardship or suffering (Riessman, 2003). Accordingly, narratives are an opportunity to gain a greater understanding of the experiences of chronically ill patients and their families (McCance et al., 2001). Chronic illnesses, such as paediatric cancer, can severely disrupt lives and there is often a demand from friends and family to know what happened and what this all means (Charmaz, 1991; Riessman, 2001). Patients with incurable diseases and their families may construct restitution plots suggesting an optimistic end, or chaos narratives suggesting no continuity between the past and a blurred future (Riessman, 2001). In turn, health professionals may create narratives of hope or of a foreshortened future (Good, Munakata, Kobayashi, Mattingly, & Good, 1994).

The use of narrative methodologies to explore illness experiences (and inform caring) is particularly relevant as it focuses on the participants' specific, individualised

stories, capturing the complex and contextual nature of their experiences (McCance et al., 2001). Personal narratives can provide a unique window into the meanings a person has constructed around their experiences, and the ways they conceptualise what has happened to them. In the case of childhood cancer, narratives from fathers of children with cancer may provide insights into how they experienced their child's cancer, and how they see the future and themselves.

### **Narrative interviews**

Within the research context, personal narratives are predominantly collected through the use of one-on-one interviews between the researcher and participants. In some interviews, researchers often dictate the ideas and themes explored through careful wording and selection of questions and topics to be directed at the participant. Conversely, during a narrative interview a potentially more unstructured and in-depth approach is taken in which the interviewer asks open-ended and broad questions inviting a participant to tell a story about a significant event in their life: "Can you tell me about..." or "What happened then?" (Riessman, 2001). In this way, narrative accounts are prioritised and the participant is given freedom to share as little or as much as they would like and are invited to guide the ideas and themes discussed within the interview. This largely unstructured interview format is perceived as one of the best ways to reveal a participant's narrative perspective, as the spontaneous language they use to narrate events is viewed as a medium of exchange that works to construct and convey their worldview (Riessman, 2001).

While narrative interviewing is not a suitable approach when canvassing large groups of participants, its strength is in providing in-depth accounts of lived experience, a strength which is well-suited to the current study. Furthermore, the narrative interviewing process brings an awareness of the process of creating and re-creating ourselves through talk, and the importance of understanding ourselves through stories. Narrative interviews can also encourage both the narrator and the listener to challenge their view of themselves and the world around them.

### **Narrative analysis**

In the human sciences, narrative analysis refers to a diverse group of approaches that have in common their focus on narrative texts (Riessman, 2003). Narrative analysis investigates the story itself and asks, what was told and why was it told that way? This kind of research aims to explore patterns of meaning making and

interpretations of events across narratives. It examines participants' narratives and analyses how they are constructed, the social, linguistic, and cultural resources they draw upon, and how the storyteller convinces the audience of authenticity (Riessman, 2003). Traditional approaches to qualitative analysis often fragment participants' accounts, taking pieces out of context and removing the structure and sequence of events (Riessman, 2003). In contrast, a narrative approach identifies longer stretches of storied talk to analyse, recognising that details are embedded within a cultural context and structured in a particular way to create meaning for the storyteller and their listeners (Riessman, 2003). Thus an investigator's job is to respect, examine, and analyse a participant's storied construction of meaning. Narrative analysis can highlight personal and collective meanings, as well as some of the social and interactional processes that shape life and human relationships (Laslett, 1999). Essentially, narrative analysis is an interpretation of a narrator's account of their experience.

Narrative analysis is governed by a number of founding assumptions about the nature of narratives (Riessman, 2001). Firstly, narrative analysis is subjective and positional, rather than objective. Researchers do not have direct access to the experiences of participants, but deal with the participant's interpretation of events - an ambiguous representation of that person's reality (Riessman, 2003). Creating a narrative requires an interactive process between the narrator and listener, and likewise, analysis of that narrative requires interpretation by the researcher (Riessman, 2003). Secondly, narratives are fluid, evolving, and influenced by subsequent life events. Each narrative provides a unique window into a person's formations at a particular point in time. Consequently, understandings generated by narrative analysis are seen to be bounded by the context of the narrative, and are not assumed to be true across different times, places, and cultures. Thirdly, it is assumed that the trustworthiness of narratives cannot be determined by traditional criteria, as there is no established or formulaic approach to the validation of interpretative work. Thus care must be taken in narrative analysis to establish trustworthiness in other ways (discussed below in the 'Issues of reliability and validity' section). Finally, narrative analysis is seen to enable the systematic study of individual meaning and experience through narratives. Researchers are able to study the self-shaping and active characteristics of human storytelling and the expression of personal identity through the powerful medium of narratives (Hinchman & Hinchman, 1997; Polkinghorne, 1995).

Narrative analysis can work to generate an integrated story as well as individual case studies of each participant in the study (McCance et al., 2001; Polkinghorne, 1995). For the purposes of data analysis, a full transcription of interviews is recorded.

Then, the boundaries, context, and structure of each narrative are identified (Riessman, 2004). Each element of a narrative's structure can be seen to have a function. According to Riessman (2003), a fully formed narrative has six structural elements: an abstract, orientation, complicating action, evaluation, resolution, and coda. These elements can be used to construct a sequential story and an evaluation of events within the narrator's world, and therefore may provide a useful lens for dissecting and evaluating narratives during analysis.

Alongside a possible focus on structure, an analysis can focus on an exploration of themes across narratives (Riessman, 2004). A thematic-based analysis of narratives can provide useful information about similarities and differences in content and what the narrator deems important to convey to the listener. Furthermore, the language of each narrative can also be analysed and compared, as language is seen as a major cultural resource that participants strategically use to construct an account of their identity and reality through social interaction (Riessman, 2004). Finally, a narrative analysis can also focus on the concept of character – the ways in which narrators portray themselves as performing particular roles, or establish and express different identities through particular actions, choices, behaviours, or relationships with other characters in the narrative. Narrative analysis through this lens can provide a dynamic approach to understanding identity and the process of creating meaning in our ever-changing world (Murray, 2003). Examining narratives through an analysis of character may provide rich insight into the narrator's constructed sense of self, identities, roles, and the influences that their cultural context may have on these constructions. In the current study, participants' understandings of what it means to be a father and a man may be embedded within narratives of their experiences during their child's cancer diagnosis and treatment.

A narrative analytical approach assumes that a storyteller has strategically created their narrative and it is up to the researcher to uncover and analyse the story as a reconstruction of the narrator's lived experience (Riessman, 2004). Consequently, the development of an overarching, integrative narrative from a number of participants' narratives may involve a consideration of how different elements shape their stories: the use of structure, themes, and character by the narrator, as well as the broader influence of cultural context. Narrative research enables the systematic collection and analysis of remarkably rich data that focuses on personal experiences (Lieblich, Tubal-Maschiach, & Zilber, 1998). The analysis of personal narratives can lead to the discovery of underlying principles which may be applied to a broader population and

can be an explorative base for research and theory development that follows (Riessman, 2008).

Narrative analysis is an appropriate methodology for the investigation of the experiences of fathers of children with cancer because it encourages the researcher to look deeply into not only the content of narratives a participant chooses to share, but also how they construct their narratives, and what this says about their view of themselves and the world. The use of narrative analysis in the current study may provide considerable insights into the meaning-making process for fathers of children with cancer, and greater understandings about the cultural context within which their narratives were formed.

### **Use of objects in narrative analysis**

While interviews are the primary means of data collection in qualitative research, interest in the use of visual methods to deepen and enrich the research process has grown (Sheridan & Chamberlain, 2011). Visual methods may include the use of material objects such as photographs, meaningful personal items, clothing, or diaries. Sheridan and Chamberlain (2011) argue that the use of objects can enhance the interviewing process by providing tangible representation of the past, increasing narrative depth, producing change in narratives, and shifting the interview process and the relationships within that. The addition of objects to interviews may engage other senses and add further dimensions to a participant's narratives.

Objects of significance are items which have meaning and worth beyond their intrinsic value assigned to them by the participant. For example, objects of significance may trigger memories, represent personal ideals or achievements, symbolise a time, place, or feeling, commemorate life events, or have implications for identity (Morgan & Pritchard, 2005; Pink, 2004). In the context of an interview, focusing on objects can encourage an increase in the depth and breadth of narratives, thus bringing about opportunities for further insight and interpretation by the researcher. More specifically, the use of objects can provide a prompt for past memories, sharpen a participant's focus, and be an everyday way to provide a visual representation of past experiences to the researcher (Sheridan & Chamberlain, 2011). Photographs in particular are often kept for long periods of time as they can provide a link to special memories and are easy to accumulate and store.

Objects can be used during an interview to provide visual representation of the past as participants talk about their experiences. In the case of documenting a child's



journey throughout cancer treatment, objects such as photographs can provide a glimpse into the highs and lows of treatment, physical symptoms such as weight loss, medical interventions, and conjure up a sense of life in a hospital room. Objects can also be used to illustrate events, document or justify actions, and support participant's narratives, thus bringing a sense of authenticity.

The use of objects in interviews can also extend and shift the flow of narratives. The presence of significant objects in an interview, such as a child's most treasured soft toy during the treatment period, or a meaningful gift, have the ability to draw a person back into the past and push vivid and emotive memories into the present (Morgan & Pritchard, 2005). In this way, significant objects can serve as a magnifying glass, prompting participants to examine and scrutinise memories of scenes, places, or people in greater detail, by bringing a focus to a broader event or a reconnection to a moment in time (Sheridan & Chamberlain, 2011). Thus, allowing talk to be informed by objects can add significantly to the intricacy of narratives shared. Photographs and other objects can also conjure up emotions and serve as a vehicle for reflection for participants, as they may experience a visual reminder of past realities for themselves and their child, reflect on what was at stake, and compare this to their current life.

As participant and researcher engage in a collaborative process of sharing and discovery, the use of objects can change the dynamics of the interview and relationships. Talk about significant items can reduce physical and emotional space between the researcher and participant by fostering a sense of shared experience. Facilitating a change in focus, by bringing attention to the objects, can also position the researcher as a third party in the interview, taking pressure off the participant (Collier & Collier, 1986). Allowing objects to inform talk can also influence how comfortable the participant feels and how much they reveal to the researcher.

The use of objects of significance in interviews can encourage narrative talk, add intricacy and depth to accounts of experience, prompt reflexivity by participants, and add to insights and interpretation by researchers. In the context of this study, where fathers were asked to share their experiences of their child's cancer, it was hoped that the inclusion of significant objects would provide a reconnection to the past and provide a multi-dimensional, multi-sensory interviewing experience for both participants and researcher. It was thought that the use of objects to inform talk in this context might bring greater clarity to vivid memories from a difficult time, and allow fathers to share, remember, and reflect upon their own journey alongside their child.



## **Issues of reliability and validity**

It quickly becomes apparent that narrative inquiry does not align with traditional criteria for determining reliability and validity. As the examination of complex and intricate personal experiences is a foundational characteristic of narrative inquiry, it is neither appropriate nor relevant to look at a lack of variation as a mark of reliability (Parker, 2004, 2005; Riessman, 2003). Variation, change, and the process of phenomena are of great interest and value to narrative researchers. Accordingly, it has been argued that traditional definitions of reliability and validity should not be applied to narrative research (Parker, 2005; Riessman, 2008). Instead, Polkinghorne (1988) proposes that narrative research is found to be reliable and valid if it presents an overarching narrative that accurately represents the experiences of participants and their constructions of meaning, as well as analysing the ways in which these have functioned to create a unified whole.

Furthermore, three guidelines which should be followed by sound qualitative research have been outlined by Parker (2004). Firstly, the researcher should carry out an extensive exploration of the field of research so as to locate their study within a solid grounding of past literature. Secondly, in a good quality study, the researcher will formulate an argument which is persuasive, coherent, logical, and flows well. An account is most persuasive when theoretical claims are upheld by the participant's narratives and when alternative interpretations of the data are carefully considered (Riessman, 2003). Finally, Parker (2004) suggests that researchers should demonstrate a level of transparency about their own background, the study's foundation, the process of research, and other possible interpretations of the issue, in language that can be understood by non-academic readers where possible. By providing evidence of research processes, for example describing how the interpretations were generated in everyday language, we can increase the accessibility, pragmatic use, and the extent to which our study can become a foundation for future research (Riessman, 2003). Parker's (2004) guidelines provide a useful framework for a sound research process and a means of evaluating the quality of narrative research, and will be used to inform the design, data collection, and analytical process of the current study.

Asking fellow researchers for interpretive input can also add to the trustworthiness of interpretations of the data and the persuasiveness of the researcher's argument (Squire, Andrews, & Tamboukou, 2008). As narrative analysis is based on finding similar themes in the narratives, discussion around the ideas and interpretations of the text can be useful to gain a better understanding of the richness

and complexity of the data (Andrews, 2008). This suggestion was carried out in the current study through the use of supervision meetings, which provided a useful sounding board and allowed the data to be analysed from the perspective of other members of the research team. By adhering to Parker's (2004) guidelines and seeking input from research colleagues, the current study aimed to produce a thorough and trustworthy analysis of the narratives of fathers of children with cancer.

## **Reflexivity**

The issue of reflexivity is an important consideration in narrative research. Reflexivity has been defined by Russell and Bohan (1999) as a process whereby researchers acknowledge themselves and those in their work through an awareness of the relational and reflective nature of the research process. Researchers must acknowledge their active participation and co-authorship in the narrative process (Hatch, 1996), both in the interactive nature of the interview and the interpretative process of analysis. The range of expectations a researcher brings to an interview can encourage and discourage the sharing of certain narratives (Murray, 2003), and also colour the way in which the researcher views and analyses the narratives later. Consulting with supervising members of the research team can be one way of increasing reflexivity as it encourages interpretations or assumptions to be discussed and critiqued.

As an active participant and primary researcher in this study, it is important to explore how my life experiences, background, chosen career path, age, and gender may have influenced the research process. My life experiences played a significant role in the creation of this thesis topic, as I developed an interest in the impact of cancer on the family following my mother's diagnosis with aggressive breast cancer when I was a teenager, and the subsequent year of treatment that followed. An appraisal of gaps in the literature then led me to focus on fathers of children with cancer. My decision to pursue postgraduate studies in clinical psychology also played a key role in the creation of this research topic, as I wanted to find a topic which would have practical and clinical implications as well as empirical significance. Simply put, I wanted my research to be meaningful and directly applicable to help others. This also influenced my decision to contact my local Child Cancer Foundation (CCF) for assistance with recruitment, and to present my research proposal in the hope that they would be interested in the outcomes of the study and be willing to consider any practical recommendations about working with fathers of children with cancer.

The way I chose and approached this topic may have also influenced my data collection process. While I did not disclose my personal experiences of a family member's diagnosis with cancer unless a participant directly asked, my knowledge of cancer treatments and protocol may have helped participants to feel at ease and share their narratives without being interrupted by technical questions (e.g. about the nature of radiotherapy, or the meaning of the word neutropenic). Furthermore, my role as a doctoral student in clinical psychology may have shaped the narratives told by participants, in accordance with their perceptions of what might be relevant to clinical psychology and their understanding of the purpose of my research. Finally, although this was the first time I have conducted interviews within a research setting, my training in clinical skills such as active listening, micro skills, and assessment, may have enhanced the interviewing relationship and helped participants to feel like they were listened to and safe to share their story. The recruitment process, through the organisation CCF, may have also influenced the construction of information as participants may have been primed to tell their stories in response to the positive or negative experiences of support they may have received from CCF, the hospital, and other organisations, as well as associated emotions such as gratitude or frustration.

Finally, basic differences in age and gender between the middle-aged fathers comprising my participants and myself as a young, female researcher without children may also have influenced the data. Personally not being a parent may have impacted the questions I asked, the ways in which I asked them, and the ways in which I interpreted participants' responses. A fellow parent of a child with cancer may have interpreted the interviews differently or elicited different narratives because of a strong sense of shared experience.

Overall, it is clear that the creation, design, and implementation of this study have been influenced by who I am as a person, and the career path I am pursuing. Awareness of this, and my place as an active participant in the research process, is an important part of the process of reflexivity. Further reflections on my experiences as a researcher and about my decisions throughout the research process will be made as appropriate in the following sections.

### **Ethical considerations**

Ethical issues are particularly salient when dealing with a topic of a sensitive nature. To a certain degree, any topic which involves exploring the personal lives of participants can be considered sensitive (Lee & Renzetti, 1990). However, whether or

not the participant considers the nature of the story to be sensitive is dependent on a number of contextual factors such as the interviewer-participant relationship, and other personal and cultural factors. It is therefore necessary to be aware of the possibility that talking about the topic may be distressful for the participant, while not assuming this will be the case (Lee & Renzetti, 1990).

The current study gained approval from the Massey University Human Ethics Committee: Northern (Application 13/006). As talking about experiences of a child's cancer could be considered a sensitive topic for the participant and may elicit an emotional response, a list of support services through CCF and alternative counselling services were made available to participants. I also tried to ensure that empathy was conveyed throughout the interviews, and was aware that I may need to offer the options of taking a break or ending the interview, if fathers became distressed. Thankfully, these options were not required by fathers at any point during the study. I was also aware of the possibility that fathers' stories of their child's cancer might trigger my own emotions. I made sure that personal supervision was available for me to discuss any personal responses to the participants' stories as they arose. I also kept a journal of my reflections about and responses to each interview as another means of recording and processing any emotions arising from the interview. Further ethical issues regarding consent, confidentiality, and anonymity will be addressed in the method below.

## **Method**

### **Participants**

Twelve fathers volunteered to participate in this study. Each father was the biological parent of a child who had undergone a course of treatment (surgery, chemotherapy, or radiotherapy) for cancer in the last five years. The children of the participants were between the ages of 4 and 12 years old during treatment, were not currently undergoing inpatient treatment at Starship Children's Hospital, and lived in Auckland, New Zealand. It was important that children were not currently undergoing inpatient treatment in order to minimise risk that a child might take a turn for the worst in between the two interviews, which could be very distressing for the father. It was decided that it would be prudent to interview fathers when their child was engaged in outpatient care, near the end of their treatment regime, or in full remission. Bereaved fathers were not eligible for the study as I was aware that their experiences could be

significantly different from those of fathers of surviving children, and the decision was made to narrow the study's focus, in order to recruit a relatively homogenous group.

Participating fathers ranged from 33 to 54 years old at the time of the interview and all spoke proficient English. When asked about their ethnicity, fathers identified themselves as New Zealand European (n=7), English (n=3), South African (n=1), and Cook Island Māori (n=1). The children discussed had been diagnosed with a variety of different types of cancer, including acute lymphoblastic leukaemia, Burkett's Lymphoma, throat and mouth cancer, T-cell lymphoma, Wilm's tumour, and Ependymoma (type of brain tumour).

## **Procedure**

The majority of participants were recruited with the help of CCF. Eligible fathers who were part of the CCF database were sent a cover letter from CCF and an information sheet written by the researcher via email or postal mail, as part of the CCF newsletter. The cover letter from CCF (see Appendix A) informed participants that the research was being conducted by a doctoral student from Massey University and encouraged fathers to consider participating. The participant information sheet (see Appendix A) contained information about the nature of the research and eligibility criteria, and invited fathers to bring objects of significance along to the interview. Eleven fathers responded to this recruitment email or letter by contacting the researcher directly and expressing their willingness to participate, and the remaining father was recruited by word of mouth through personal networks.

After being contacted via email or phone by interested fathers, I asked questions to confirm eligibility for the study, answered any questions they had, and scheduled the initial interview. Participants were given the option of being interviewed at their own homes, the CCF buildings, the university, or at their workplace. All interviews took place face-to-face at the preferred location of the participant.

Before the official start of the interview, the participants were introduced to the researcher, reminded of the nature of the study, and asked to fill out a participant consent form (see Appendix B). If fathers brought along significant objects to the interview with them, they were asked for permission to photograph the objects, and then to fill out an image consent form (see Appendix B) to give permission for the use of each photograph that was taken in research and publications. If appropriate, the image consent form was sent home between the first and second interview so that fathers could obtain consent from other members of their family. This measure was

taken to ensure that a photograph of a child or other such object, which could be used to identify a child or father, would not be used or published without full permission and consent from the child themselves (if old enough to understand and consent) and appropriate family members. At the end of the interviewing process, fathers were reminded that they would be sent a summary of findings (see Appendix C) at the conclusion of the study and thanked for their participation. In appreciation of their time and effort contributing to this study, fathers were gifted petrol vouchers.

## **Interviews**

Narrative interviews were the chosen method of data collection for this study, as they were seen to be an effective means of eliciting participants' stories about their experiences of their child's cancer in everyday language. I was interested in how fathers' stories, and use of language in the telling of these stories, made sense of their experiences and created meaning around their journey through their child's cancer. The interviews were voice-recorded, with the consent of participants, so that the content of the interviews could be accurately transcribed and analysed. Following each interview, and again after transcribing the interview, I took analytic notes, recording my initial thoughts, reflections, and observations.

The interviews were conducted in a collaborative, conversational manner where interviewer and participant worked together to illuminate meaning behind the stories shared (Polkinghorne, 1988; Riessman, 2008). Fathers were deliberately given time and opportunities to share their experiences, increasing the likelihood that their talk would take the form of stories, and giving me a greater understanding of how events played out from their perspective (Polkinghorne, 1988; Squire et al., 2008). At the start of each interview, I introduced myself, explained the purpose of the interview, and expressed my interest in hearing about their experiences as a father of a child with cancer. This then directed the course of the interview and guided the type of information fathers shared with me. Fathers were also loosely guided by a general list of questions which were asked as a natural part of the flow of the conversation, allowing them freedom to answer and share their story in ways they felt were relevant. There was a lot of flexibility in the interview, as I allowed participants to share whatever information they perceived as relevant to my purpose, assuming that what they said and the way in which they expressed themselves was an important part of their meaning-making process.

The initial intention was to conduct two interviews with each participant, as it has been suggested that this may help increase the richness of the information given (Legard, Keegan, & Ward, 2003) by allowing participants additional time for reflection and recollection of memories between interviews. It also allowed me, as the interviewer, extra time to reflect on areas that might be useful to explore in greater depth with the participant. Furthermore, the time between the two interviews was practical in allowing fathers to gain appropriate consent from family members for the photographing of any objects of significance. Having more than one interview may also have also positively impacted on the research relationship, as it gave more time for me to build rapport and may have lead to the participant feeling more comfortable (and perhaps less nervous) about sharing about his experiences in the second interview.

However, conducting two interviews with each participant was not always possible, as several fathers stated a preference for one longer interview, instead of two shorter interviews, because of work or other commitments. Similarly, some fathers felt as though they had shared everything they wanted to by the conclusion of the first interview. As a result, six fathers engaged in two interviews, and six fathers engaged in one longer interview. Fathers who did not return for a second interview were asked to ask other members of the family to sign the image consent form (if relevant) and to scan and email this back to the researcher. Interviews with fathers ranged from 45 to 150 minutes for the initial interview, and were generally shorter, between 15 to 45 minutes for the second, follow-up interview. After two interviews with each of the twelve fathers, a number of recurring themes had emerged and it was clear that data saturation had been reached. Transcription of the audio files took place in the months following interviews, by the researcher and a professional transcription service. The professional transcription service was asked to sign a confidentiality agreement to ensure that participants' information and identities were protected.

Ten fathers chose to bring along objects of significance to their interview. Objects included their child's beads of courage (n=6); photographs of their child during or after treatment (n=4); their child's radiation mask (n=2); medical objects such as portacaths (a device inserted under the skin to allow long-term intravenous access), hospital identification bands, tubes, or medicine bottles (n=4); and other significant objects such as their child's favourite toy, food, or gifts given during treatment (n=4). These objects were helpful in eliciting stories from fathers and providing a visual representation of experiences during their child's cancer treatment.



## Data analysis

The aim of my analysis was to explore the experiences of fathers of children with cancer through a narrative framework. More specifically, I hoped to uncover and generate insights into fathers' personal and shared social meaning-making, identity construction, and the discourses of fatherhood and masculinity within which these occurred. This particular focus is an integration of two analytic lenses described by Chase (2005) - the first focusing on the narrator's voice and their choices, and the second focusing on the way the narrative is socially embedded. Furthermore, I hoped that my analysis of the data would inform clinical practice for health professionals working with this population by facilitating further understanding of father's experiences and needs.

From the beginning of the data analysis process, I was aware that I was being entrusted with each participant's story, and the enormity of the task of creating my analysis in such a way as to give justice to the richness and depth of the personal stories and insights that were shared. This sense of responsibility to represent the data in a meaningful and coherent way is a common experience of narrative researchers (Hunter, 2010). Data analysis began during the interviewing process, as I took notes following each interview to record my initial reactions, observations, and reflections on the participant's narratives and interviewing process. As noted by other qualitative researchers (Russell & Kelly, 2002), it is important to be aware of our responses during interviews and why we might have these responses, so we can be critically aware of how we perceive and make sense of the data (Michalowski, 1997). I also took notes on the similarities and differences between each interview and earlier interviews by other participants. These notes were then developed following my transcription of the earlier interviews, or reading of the latter third of the transcripts, which were transcribed by a professional.

While I found the transcription and re-reading processes to be effective in etching participants' stories into my memory, I also found it frustrating as the messiness of the data became increasingly apparent. I noticed that I often interrupted the flow of the participants' speech with minimal encouragers, and that both the participant and I often spoke in fragmented sentences with rampant grammatical and linguistic errors. I had to resist the desire to smooth over the transcript by correcting such errors, particularly in portions of the transcript I recognised as potentially valuable to my analysis. My discomfort with the messiness of the data seems to be consistent with the experiences of other qualitative researchers (Emerson & Frosh, 2004), but may also be particularly salient for me due to my background in statistics and quantitative research.



After all interviews and transcripts were completed, the second stage of my analysis was to further immerse myself in the data. This immersion in the data through listening to and reading transcripts has been referred to as a kind of “embodied knowing” (Hoskins & Stoltz, 2005). By listening to each interview again, each father’s manner of speaking, tone, and emotional changes throughout the interview became more evident. In this way, as I read and re-read the transcripts, the way in which fathers had conveyed particular quotes was forefront in my mind. This enabled me to have a ‘feel’ for the data and the meaning behind particular quotes as I continued to read. Each time I re-read the transcripts, I incorporated new observations and insights which deepened my understanding of the data (Emerson & Frosh, 2004). In the initial stages, broad topics and themes across the fathers’ accounts were most readily apparent. However, as I examined the data, I was also aware of how my presence and questions as a researcher had shaped the content of the data (Riessman, 1993). As acknowledged by Creswell and Miller (2000), the researcher and the inquiry process are inseparable. Because of this, it was important not to become bound by any initial categorisations of data which may have been anchored in the participants’ perceptions of what my research interests were. I wanted to go beyond themes such as employment, relationships, and emotional struggles, to explore the way participants constructed their accounts and to discover the meaning behind their stories.

Therefore, the next step in my analytic process was to search for and identify narratives within the transcripts. This task was not as simple as it initially sounded to me, as I found that it was hard to define exactly where a narrative began and ended. Again the messiness of the data was painfully apparent – participants often changed tack in the middle of a story, spoke in fragments, or trailed off as if no words could explain further. I also became aware of the layering of stories within a participant’s transcript. Some fragments of more specific stories were also part of larger stories told by a participant. As a result of these difficulties, I decided to trial a strategy for narrative criticism recommended by Pellico and Chinn (2007): to begin my search with an examination of the pivotal moments for each participant, the strengths and insights they identified, and the elements they deemed to be important within the stories they shared. To accomplish this, I went through each transcript in detail, pulled out quotes and passages which encompassed pivotal moments and ideas as identified by the participant, and recorded these in a separate document for each transcript. For each passage or quote I identified, I asked myself a number of questions:

- Why has this been identified as a pivotal moment or idea and what makes it pivotal?

- What is the underlying message the father is trying to convey?
- What narrative devices is the father using and for what purpose?
- What kinds of social identities are being constructed and for what purpose?

The next step was to group together similar quotes, moments, or issues which were consistent across participants' accounts. This resulted in 55 provisional sub-headings, which I grouped under eight preliminary headings:

- Struggling to be a protector
- Father as provider
- Expectations of fathers' role in family
- Strength and vulnerability
- Physical stress
- Changing responsibilities in crisis
- Changes in family dynamics
- Meaning making

While I found that this exercise was useful in uncovering broader ideas in the data, I wanted to move away from a thematic appraisal of the data and focus more specifically on an exploration of narrative elements in the data. In this process, I explored a number of narrative avenues, to see which provided the best fit for my data and enabled me to create a coherent overarching narrative that did justice to the participants' accounts. Firstly, I explored the importance of plot by viewing the data through a chronological framework: fathers' progression from diagnosis, through the different stages of treatment, and out the other side to post-treatment reflections. While I found this categorisation of the data a helpful starting point, I wanted to explore fathers' experiences on a deeper level. The next avenue I explored was viewing the data from a structural perspective, in particular, looking at conflict and resolution. These two aspects of plot were chosen because they seemed to be key story elements: due to the nature of cancer treatment, each father's account was full of stories of obstacles and challenges that they and their child had struggled through or overcome. However, it was hard to define and then sift through the abundance of conflicts and resolutions in each participant's story. While this emphasised the importance of capturing the breadth and depth of each fathers' emotional, physical, and social challenges through my analysis, I felt that focusing on conflict and resolution did not provide me with the key I need to construct a clear and comprehensive overarching narrative.

As the concepts of identity, role, and a socially constructed sense of self are central concepts in narrative inquiry (Hunter, 2010; Polkinghorne, 1988), it seemed prudent to next explore the analysis of character as a key narrative element in the fathers' accounts. According to Neimeyer (2000), narrative can be used as a metaphor in the reconstruction of the self. I was interested in examining the socially-embedded roles that fathers constructed for themselves through their narratives. There seemed to be a good indication that this avenue would be fruitful by the emergence of roles such as protector and provider, and topics such as expectations of a father's role and changing responsibilities, in my initial headings. I re-read the data I had identified under my initial headings, firstly asking myself if the construction of roles was a key component of narratives shared in a broad sense, and secondly asking myself a number of more specific questions:

- Which roles are identified in the data? Which roles are seen as most important by fathers and why?
- How are these roles constructed and established by fathers?
- How do fathers negotiate changes in role and identity?
- Are these roles specific to the cancer context or are they extensions of roles that fathers commonly take upon themselves?
- What resources and social discourses do fathers draw on in the construction of roles?

Although the stories shared by participants were unique, there were some commonalities in the ways in which fathers experienced and struggled with role changes during the course of their child's cancer. Fathers constructed themselves as different characters throughout their child's cancer journey, and it is their struggles with taking on these different roles and identities which offered to provide a vivid and rich account of their experiences and a deeper understanding of what it means to be a father of a child with cancer. In this way, I hoped to go beyond previous approaches in the literature which have focused on parents' maladjustment and coping experiences of their child's cancer (Nicholas et al., 2009; Sawyer et al., 1998) and instead draw attention to how fathers position themselves in their narratives regarding roles, identities, and social expectations, and the ways in which this impacted upon their experiences.

As a result of looking at the data from the perspective of character, I drafted a list of sixteen provisional roles. Some of these roles were thrust upon fathers, while other roles were chosen by them. Each role presented its own challenges of adjustment and identity. I found uncovering the crucial importance of role and identity for the narratives

that fathers shared with me surprisingly rewarding. It quickly came apparent that each pivotal moment was anchored in questions of role, identity, and responsibility for the father. I was also heartened by the commonality in fathers' experiences as they described tensions and challenges associated with the different roles they performed. I observed that a number of the roles I uncovered were not dissimilar from those I might identify in the accounts of fathers of healthy children; however, the demands and challenges of those roles were heightened by the crisis of cancer. For example, participants spoke of the challenges associated with being a Husband and Father during cancer treatment. These are roles they were familiar with and had experienced in their normal lives prior to the cancer diagnosis. However, in the stressful and high intensity context of cancer, fathers described struggling to adjust to the increased emotional needs of their partner, as well as difficulties in juggling time between their sick child and their other children. Other roles were more time-limited and specific to the cancer experience, such as the role of Infection Policeman.

At this stage, it was also important to define what exactly what the term 'role' meant and whether this was the best term to use in my analysis. A number of discussions with my supervisors took place to determine how best to define the ways in which I had explored the notion of 'character' within my narrative analysis. Were these best described as roles, identities, positions, functions, or perspectives of fatherhood? As different words have varied associations and meanings for each person, it was useful to discuss the benefits and limitations of each term. In the end, I decided that the term 'role' was the best fit as it worked in well with narrative ideas that a father might perform a role that he feels is expected or dictated by social discourses of fatherhood or masculinity. A 'role' captures the idea of a narrator choosing how to portray a character within a story and their responses to the challenges they face. It followed that the fathers in this study constructed an account of themselves performing different roles of fatherhood as they responded to the challenges of their child's cancer diagnosis and treatment. Within this context, roles are seen to be fluid, interrelating, and could be transitional or ongoing. For example, a man might act within the ongoing roles of Father and Husband while also attending to a temporary need to step into the role of Decision Maker. Roles also encompassed a breadth of focuses: they could be centred on relationships, such as the marital relationship; on responsibilities, such as that of providing for the family; or on emotional wellbeing, such as the need for strength and support. The decision was also made to capitalise the names of roles used in the analysis, in order to emphasise these as key components of the analysis and to clarify

when they were being referred to. This was particularly useful in separating the discussion of the role of Father from general references to fathers in the study.

The next question I grappled with was how to structure these provisional roles into a coherent narrative. Initially I trialled a chronological approach that grouped roles by the different stages of treatment within which they were most prominent:

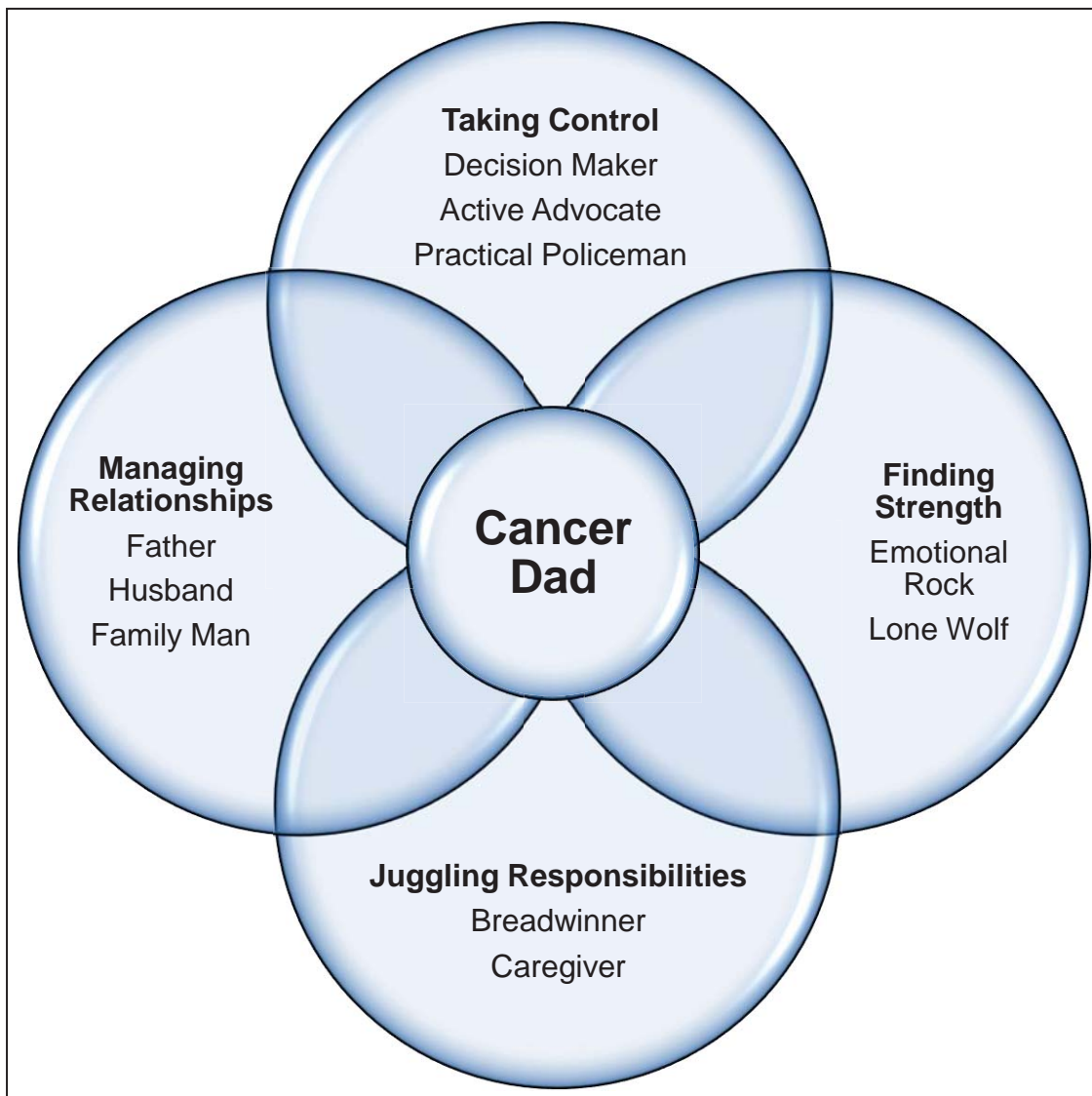
1. Diagnosis
  - a. Cancer Dad
2. Taking control
  - a. Decision Maker
  - b. Active Advocate
  - c. Infection Policeman
3. Long haul of treatment
  - a. Practical Dad
  - b. Emotional Rock
  - c. Protector of the Sick
  - d. Lone Wolf
4. Caregiving
  - a. Breadwinner
  - b. Caregiver
  - c. Tag-team Parent
5. Relational changes
  - a. Father
  - b. Husband
  - c. Family Man
  - d. Friend

While this was a helpful initial step towards organising the data in a coherent way, after discussing the proposed structure with my supervisors, it was also apparent that there were some inherent problems with a linear structure. While some roles emerged during a particular stage of treatment, fathers did not progress through roles in a linear fashion. It is also evident that earlier roles, such as Cancer Dad or Active Advocate, did not end before the treatment phase begun, but were an important component throughout the entire journey. Similarly, relational roles such as Father or Husband were continually held by fathers throughout their journey, and it would have been misleading to introduce these near the end of a chronological structure. Roles within caregiving also did not seem to be accurately represented by a linear or chronological timeline for this reason. Furthermore, while the role of Cancer Dad was

initially viewed as a reaction to diagnosis and the recognition that life would be different for the duration of cancer treatment, it became apparent that this role was central to fathers' experiences throughout the cancer journey. The role of Cancer Dad was seen to continue throughout all other roles and to have an important effect on fathers' behaviours and expectations in the subsequent roles.

Consequently, a new structure was proposed to address these issues (see Figure 1). It was decided that in order to better represent the messiness and overlap inherent within the roles played by fathers, overlapping circles would be used to pictorially represent fathers' roles in place of a chronological timeline. These overlapping circles are used to symbolise the way in which fathers are constantly juggling or holding in place multiple roles during their child's cancer journey. During the crisis of cancer, fathers experienced the changing demands of more long-term roles such as that of Husband and Caregiver, while also managing more temporal and specific roles such as that of Practical Policeman. I saw the role of Cancer Dad as central to fathers' experiences of other roles, and therefore this role was placed at the centre. In this way, the analysis focused on fathers' constructions of their role as Cancer Dad and how this was manifested throughout a number of more specific roles.

The more specific roles of the new narrative structure were categorised into four different groups, similar to the previous groupings, as represented by the four overlapping circles (see Figure 1). However, I decided to go through a process of consolidation and refine the roles included under each group to make a more coherent structure. I went back to my initial notes when I first examined the data in search of roles that fathers had constructed to look at the relative importance of each role for fathers, the different ways this role manifested across different fathers' accounts, and the overlap between this role and other roles represented. As a result of this consolidation process, I decided to combine the roles of Practical Dad and Infection Policeman under the heading of Practical Policeman, as there was a lot of overlap in the practical ways in which fathers addressed their child's infection susceptibility and other needs. Secondly, I found that the role of Protector of the Sick could be found within the roles of Practical Policeman and Emotional Rock, and decided to remove the role to prevent the repetition of information. Thirdly, as the role of Lone Wolf encompassed fathers' ideas around seeking support and the importance of social networks, I decided that the role of Friend could also be excluded. Finally, I decided to omit the role of Tag-team Parent, as the challenges of balancing the responsibilities of Breadwinner and Caregiver would be better discussed within each of those two roles. After this consolidation process, there were ten secondary roles remaining.



*Figure 1.* A diagram showing a visual representation of the structure of my analysis, with Cancer Dad as the central role, surrounded by four key ideas with subsidiary roles.

The four groups were then looked at to ensure that grouping made sense and that the headings accurately represented each group. The first group, which included the roles of Decision Maker, Active Advocate, and Practical Policeman, was labelled 'Taking Control' as a reflection of the way in which these roles were a means of regaining the control fathers that felt they had lost following their child's cancer diagnosis. The second group, which included the roles of Emotional Rock and Lone Wolf, was labelled 'Finding Strength' as both these roles were seen to reflect fathers' struggles to find the inner strength to carry on and to support their families. The third group, which included the roles of Breadwinner and Caregiver, was labelled 'Juggling Responsibilities' to reflect the extent to which these roles represented a struggle to balance responsibilities to provide for the family financially, and to fulfil caregiving



duties. The final group, which included the roles of Father, Husband, and Family Man, was labelled 'Managing Relationships' as each of these roles centred on fathers' relationships with those around them. The use of these four groups to define roles provided a useful structure to enable me to discuss more similar roles alongside each other in depth, while also covering the breadth of the experiences of fathers of children with cancer across the four groups.

Throughout the process of data analysis, it was apparent that the objects of significance brought along by fathers to the interview were an integral part of the research process and fathers' constructions of their roles. The objects of significance became narrative devices which provided tangible representation of fathers' accounts, provided a focus for the deepening of narratives, provided a multi-sensorial experience of fathers' narratives, and strengthened the researcher-participant relationship through a sense of shared experience.

While recognising the importance of these objects and their central place in the analysis, I was also aware of my desire to preserve the anonymity of my participants and their children. When looking at photographs of objects, I was aware that a number of them had identifying details visible. For example, the beads of courage included beads with the child's name on them, and photographs of medical identification bands or portacaths also showed the child's full name, along with other personal details. Although full consent for use of the photographs in research and publications was given by each father, I felt uncomfortable displaying photographs with identifying information as a part of my thesis or related publications, as I was aware that those children will grow up and may feel uneasy or embarrassed that they might be identified from those photographs. In order to protect the anonymity of my participants and their children, I decided to digitally alter the names visible in photographs taken of children's beads of courage and to blur out any identifying information in other significant objects, such as the child's name and NHI (National Health Identification) number, on any photographs with medical information visible.

Although some fathers brought along photographs of their child during treatment, I decided to exclude these from my thesis and any resulting publications as it would be too difficult to conceal the identity of the child within the photograph. Cancer treatment can be a very difficult time for children, and they often experience alterations in appearance such as a 'moon face' due to steroid use or hair loss due to chemotherapy. Consequently, I decided that as my participants' children will one day grow up and may feel embarrassed about seeing photographs of themselves during cancer treatment, it was best to exclude these from my final analysis.

When looking at the objects of significance brought by fathers to the interviews, it was notable that six of the twelve fathers brought along their child's beads of courage. I felt as though this was a significant avenue to pursue and warranted further exploration of how the beads might be used as visual storytelling devices by fathers. Although several beads of courage photographs were included within the roles of Active Advocate and Emotional Rock in the main analysis, I felt as though it was also important to also write a separate paper which focused solely on the beads of courage and their significance as a narrative device for fathers of children with cancer. To date, only one study (Baruch, 2010) has investigated the perspective of parents on the Beads of Courage programme, and this was seen as an opportunity to contribute towards the evidence-base supporting this worthwhile programme. This paper is included in the appendix (Appendix F), and has been submitted to journals with the intention of achieving publication. Furthermore, the paper was presented to the local CCF branch, who communicated that this would be a useful resource for them in promoting the effectiveness of the Beads of Courage programme within their organisation and in securing ongoing funding for this.

Overall, twelve photographs of objects brought along to interviews by fathers were included in the final analysis. These were used throughout the analysis to provide visual impact, reinforce the stories told by fathers, and to increase the richness of the reader's understanding of what it meant to be a father of a child with cancer.

### **Summary**

In conclusion, a social constructionist and narrative inquiry approach were chosen to enable the exploration of how fathers of children with cancer construct their experiences and sense of self through the narratives they chose to tell. The current study used narrative interviewing to collect information from twelve fathers of children with cancer, which was then analysed using a narrative process, as discussed above. The narrative analysis process was a lengthy but valuable experience which resulted in the decision to represent fathers' accounts through an analysis of the construction of roles throughout the cancer journey.

## Chapter Three

### Cancer Dad and Taking Control

This chapter commences with an exploration of the broad, overarching role of Cancer Dad and a discussion of fathers' constructions of this role. I then examine the ways in which the role of Cancer Dad is manifested through a number of more specific secondary roles. The first group of roles, which are discussed in this chapter, pertain to the idea of taking control, as following the initial shock of cancer diagnosis, many fathers felt driven to regain control of their child's situation. This idea of taking control, while in the role of Cancer Dad, is explored through discussions of the secondary roles of Decision Maker, Active Advocate, and Practical Policeman. The following three chapters then discuss the secondary roles pertaining to finding strength, juggling responsibilities, and managing relationships respectively.

#### Cancer Dad

A child's diagnosis with cancer can be one of the most shocking and devastating moments in a father's life. For many fathers of children with cancer, this moment of diagnosis can represent a striking biographical transition (Young et al., 2002) as they are forced to re-evaluate many of the roles and responsibilities associated with their identity as a father. The moment of diagnosis carries an abrupt realisation for fathers: not only has their child been diagnosed with cancer, but their own identity has changed - they now are a Cancer Dad. They have been thrust into a role which they had not anticipated, a role which is heavily laden with responsibilities regarding the wellbeing of their child. While fathers are not unwell themselves, they often experience many of the consequences of chronic illness, such as biographical transition, changes in role, increases in responsibility and decreased quality of life (Young et al., 2002). The idea of this sudden biographical shift from 'normal Dad' to 'Cancer Dad' is supported by the strong physical imagery used by several fathers as they describe the moment of their child's diagnosis:

It was like a smack between the eyes. Absolute bombshell. Disbelief, fear, you know, just so many emotions. *David*

It's a real shock. I mean it's like being smacked in the guts with a sledgehammer. *Ryan*

David and Ryan described the physical force of the diagnosis in ways which convey the devastation they felt at their children's diagnoses and the secondary shock that they were now Cancer Dads. Both fathers used images of external force to signify their role transition, suggesting that they felt that this was beyond their control. The new role of Cancer Dad was thrust upon these fathers by external factors, rather than being chosen. The images of a "smack between the eyes" or being hit in the "guts with a sledgehammer" also highlight the enormity of the cancer diagnosis for these fathers and the realisation that their lives were changed at this moment. This sense of being overwhelmed and that life will never be the same, has been reported as a common experience across fathers of children with life-limiting illnesses (Ware & Raval, 2007).

These emotions were overwhelming for some fathers who struggled to accept the reality of their child's cancer diagnosis:

We just stood there and looked at each other and thought, oh my God, what's going on here, this doesn't really happen to normal people. This happens to other people. *Jack*

Jack expressed difficulty reconciling his new role as a Cancer Dad with his previous role as a "normal" Dad, where he felt distanced from the crises that happened to "other people". By clinging on to assumed normality and viewing himself and his wife as separate from "other people" in crisis, Jack had never grappled with the possibility that his child could be diagnosed with cancer. His disbelief at the presence of cancer within his own family is shared by Ryan:

You never think it'll be cancer, or anyone in the family will get cancer.

Receiving a cancer diagnosis is a pivotal moment in which an assumption of normality can be severed (Tobin & Begley, 2008). To adapt to their role as a Cancer Dad, fathers need to move past their disbelief, realise that their family is no longer "normal", and accept the reality that their child has been diagnosed with cancer. There is a clear sense that ordinariness and predictability of everyday life has been lost and fathers must adapt to the uncertainty of life as a Cancer Dad. Tobin and Begley (2008) also suggest that the transition from the known to the unknown can trigger a search for meaning and answers. In their journey to accept the reality of their role as a Cancer Dad, many fathers grapple with fears and uncertainties about their child's future:

Well, yeah, devastation. How else can we say it? We just fell apart. What do you do? It's the last thing, because you think, well, there's an end here. There's no cure to this. At first it's scary, very, very scary ... We were just devastated. *Max*

I just remember not knowing what to do and lying there in the hospital, thinking, “Crap, how do we get through this, is he going to be alright?” Because there was a period where you don’t know, you really don’t know.

*Mark*

It’s the worst thing ever. She said to me twice, “Daddy, I’m dying”. To hear that it’s ... *Dan*

The reality of diagnosis can be not only shocking, but very frightening for fathers, as they come face to face with the uncertainty of their child’s situation and the fear that they could lose their child to cancer. Questions and accompanying worries about their child’s health and future can represent key stressors for fathers (Cayse, 1994), particularly in the period following diagnosis. The uncertainty around their child’s diagnosis, treatment, and outcomes can be very distressing. Fathers, such as Mark, alluded to the fact that as a Cancer Dad they felt completely disoriented and didn’t “know what to do”, while other fathers, such as Dan, struggled to express the intensity of their emotions at the realisation of their child’s mortality. This sense of helplessness and the struggle to deal with uncertainty sent fathers on a search for clarity and answers in the midst of the chaos they were experiencing:

And then you start thinking, how did he get it, where did it come from, what have we done to make it happen? Is he going to die? *Ryan*

What have I done wrong? That’s the biggest question of all that comes up – why? What have I done wrong, or what am I doing wrong? It’s never what you’re doing right; it’s what you’re doing wrong. *Andrew*

I was very vocal. Screaming out and saying, “What the hell? What’s going on? It’s all bollocks. Why does our child get this? Why? What’s she done wrong?” That’s what you think. And we still sort of think that in some ways. What have we done wrong to deserve that? *Max*

Fathers described desperately searching for answers about the origin of their child’s cancer as a key struggle in their role as a Cancer Dad. Questions such as “what have I done wrong?” and “how did he get it?” plague fathers as they struggle to understand why it was their child who was diagnosed with cancer and if they could have done anything to prevent it from happening. Fathers described a tendency to think negatively and to look for blame in their desperation for answers. The emotional intensity felt by fathers is conveyed by Max’s honest admission of “screaming out” and being “very vocal” as he grappled with the lack of reasons for his daughter’s diagnosis with cancer. This passionate quest for clarity and answers has been described by Ware

and Raval (2007) as an attempt by fathers to find order or reason in the midst of chaos. The questions that fathers ask at this time of crisis reveal their inner struggle with the tension they feel between their new role as a powerless Cancer Dad and their traditional role as the protector of their children. Have they failed in their role as protector of their children? Have they done something wrong, or neglected to protect their child from the source of the cancer? In this way, a child's diagnosis can profoundly shake up fathers' views of themselves and of the world.

While grappling with questions and the reality of their child's cancer diagnosis, fathers often found themselves initially dependent on medical staff to step in and take charge of the situation. Children usually started treatment almost immediately after diagnosis so there was often little time for fathers to digest the large amount of information about their child's type of cancer and to feel equipped for involvement in decisions about corresponding treatment. In this initial stage of a cancer diagnosis, Jones and Neil-Urban (2003) propose that health professionals often act as surrogate parents. The need to rely on hospital staff for expertise and decision-making left fathers struggling with a sense of powerlessness:

It was just, sort of, very stressful spending time and trying to help Michael and do what you can when you really can't do anything. You just haven't got the expertise like the doctors and nurses. *Mark*

Put a physical threat in front of a man, he can deal with it. But you put something that you can't hurt or scream and punch into submission, it's a different story altogether. *James*

Fathers found it "stressful" when confronted with a threat to their child that was not physical – they could not "scream and punch" the cancer into submission. For many fathers, their child's diagnosis with cancer triggered an overwhelming realisation of their lack of control. Furthermore, without the medical "expertise" they attributed to health professionals, most fathers felt lost in the hospital environment and powerless to help their child in the initial stages of their cancer treatment. This was a disorientating and distressing experience for fathers, and many struggled to find ways to feel helpful in their new role as a Cancer Dad.

Each father's transition into the role of Cancer Dad was marked by an abrupt change in perspective, an adjustment to the reality of their child's diagnosis, a search for clarity and answers, and a struggle with a sense of powerlessness. It is clear that their child's cancer diagnosis was a devastating event for fathers in a number of ways,

and had a profound impact on the way fathers viewed themselves and the world, during the initial stages of cancer treatment.

Fathers were required to assume a number of overlapping, complex, and sometimes contradictory roles throughout their cancer journey. In this way, fathers grappled with and experienced many secondary roles while in the broader overarching role of Cancer Dad. Some of these roles were specific to a particular stage of treatment, while other roles involved redefining more permanent roles such as that of caregiver or husband. While secondary roles are discussed below in a linear fashion, the reality is much messier: it is clear that fathers hold and act out numerous roles concurrently and move fluidly between roles. At the core of these different roles and experiences is a growing understanding of what it means to be a Cancer Dad; this is the common thread which binds each role and each father's narrative together.

## **Taking Control**

### **Decision Maker**

Following the diagnosis of cancer, and fathers' struggles with a sense of powerlessness, one of the key objectives for fathers was to establish some control over their child's situation. This desire to re-establish control is often described by fathers of children with serious illnesses as a key coping strategy (Ware & Raval, 2007), as being able to take charge in even small areas can help fathers to reduce their feelings of helplessness. One way that fathers established control was through taking upon themselves the role of Decision Maker. While fathers were thrust into the role of Cancer Dad, assuming the role of Decision Maker was a deliberate choice based around a desire to take charge and re-establish control of their child's situation. After the initial shock of diagnosis, fathers commonly expressed a desire to become more involved in their child's treatment and contribute to treatment decisions. For many fathers, the ability to have some say over their child's treatment was a powerful way of regaining a sense of control and a feeling of usefulness.

One father, Luke, illustrated his transition to the role of Decision Maker through taking control of the timing of his son's brain surgery:

So me and my wife had to make a decision whether to have that operation on that day or let him have a Christmas. So my wife was saying let him have a Christmas, and everyone was saying let him have a Christmas, but I said nah, he's having that operation, because the longer we leave it, the



riskier the operation. “Are you sure?” I said, “Yep. Don’t doubt it; he’s going to have the operation”.

By taking upon himself the role of Decision Maker, Luke perceived he was able to protect his child from further risk associated with delaying neurosurgery and in doing so was able to reinstate his sense of control over his son’s situation. In this case, his decision was final for the family and he carried the final responsibility for any consequences of his decision. Another father, Andrew, also described taking on the Decision Maker role for initial decisions surrounding his son’s treatment:

Some of the decisions we made early on weren’t decisions that we made, they were decisions that I made, because my wife wouldn’t, in fact, couldn’t make them. I was like, “we’ve got to trust the medical people that they know what they’re doing and they’re giving us the right information. We go down this route and we trust them”. “Yeah, but what ... no, I don’t want them doing that”. “We’re not thinking of you, we’re thinking of our son”.

Early decision-making fell to Andrew as he felt his wife was too overwhelmed by the stress of their son’s diagnosis to be involved in decision-making. Despite the perception of control, Andrew highlights the vulnerability of his situation: the circumstances force him to “trust” in the competency and disclosure of the medical practitioners while still considering the impact any decisions might have on his son. As Andrew explains to his wife, decisions must be made not based on what they would like done in the situation, but on what they believe is best for their son. Decision-making must weigh up the medical expertise of the health professionals with the expertise and emotional investment of the parents in their own child (Clarke & Fletcher, 2003). Andrew acknowledges that he must “trust” the medical team for their knowledge but he must also trust in his own knowledge of his son and what would be best for him. In this way, Andrew reminds us of the importance of collaboration and trust in the relationship between practitioners and parents in decision-making. Trust has been reported to have a significant influence on decision-making among parents of children with cancer (Hinds et al., 2000) and has been argued to be an influential factor in the development of a working relationship with families of children with chronic conditions (Gruccio & Steinkrauss, 2000).

For many fathers, assuming the role of Decision Maker was a steep learning curve:

You know nothing about what’s happening, and suddenly within a short space of time you have to become an expert on all sorts of things. You have

no idea really, what chemotherapy was and what it meant and how it was given and yeah, the different options. *Mark*

As well as learning about their child's treatment and trying to make informed decisions regarding medical options, fathers also described being confronted with more personal decisions such as whether they should shave their child's head. Andrew describes taking on the role of Decision Maker in order to protect his family from what he perceives to be the negative effects of watching his son lose his hair slowly:

For me, the hardest part was the first two weeks ... It's getting all the results, it's them saying, "Do you give your consent for this? Do you give your consent for that?" And then running through it all and then one of the other decisions that we had was, my wife was, "Oh, well, we'll just leave his hair as it is". And I said, "No, shave it. Trust me, you're going to be far better just getting it all cut off rather than watch it all come out. I've seen it happen before, it's far better, just do that," and that's what we did. Saw other children that came in and they just let it come out gradually and you could see the effect it was having on them – the parents and on the children. *Andrew*

Fathers also constructed the role of Decision Maker as one which was "fraught with worry" about the long-term implications their treatment decisions may have and which decision would be most protective of their child. David is one such example of this, as he struggled to decide if the possible benefits of radiotherapy for his daughter's brain tumour outweighed the unknown long-term side effects:

The decision that we made, it was fraught with worry. Do you give a large dose of radiation to the brain of a five-year-old? Damned if you do, damned if you don't. There was no benchmark to say this is my daughter now, this will be her post-operation, and this is what it could mean. But certainly we understood there will definitely be some effect on her, but one of the things I was particularly worried about for little girls was losing their hair. You know, just starting school in the middle of radiation treatment.

While David indicates that the decision was shared with his wife, his use of "my daughter" seems to indicate that he feels a particularly strong sense of responsibility toward his daughter. He is challenged by the complexity of the decisions to be made – what does it mean that a decision to use radiotherapy to treat her brain cancer might also harm her brain functioning and impact her in unknown ways in the long-term?

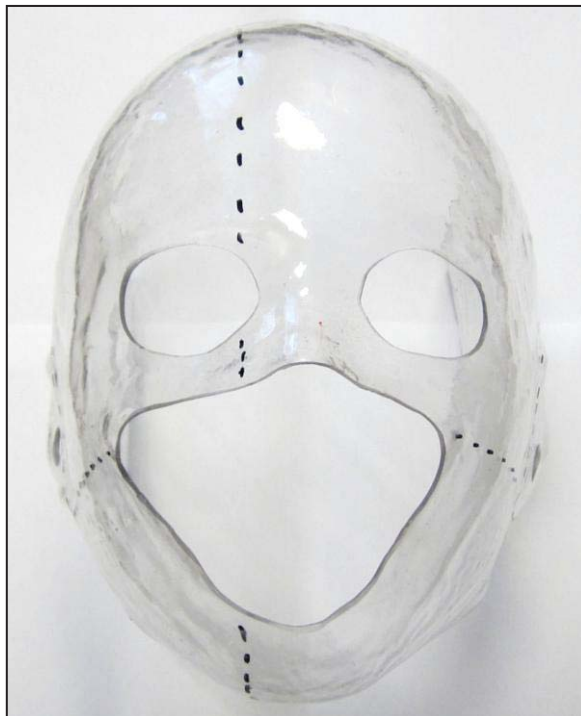
David is also mindful of the way in which short-term effects, such as hair loss, may impact upon his daughter's start to school.

Andrew was also worried about the decision to allow his son to undergo radiation therapy for a throat tumour and the consequences this may have for his son:

Obviously, our concerns with having radiotherapy treatment so close to his brain are that he'd get some form of damage.

Andrew chose to bring along his son's radiation mask (see Figure 2) to enrich his narrative and to provide visual representation of his worry about his son's experiences of radiation therapy, and the possible consequences of this. For Andrew, this mask was a powerful narrative device which prompted clear memories of his son's experiences of radiation therapy, and provided a way to communicate the stark reality of this procedure to the interviewer:

For his radiation side of it, he had to have a mask made and what they do is that mask goes on his head, he goes on the table and it's then fastened to the table and everything else to keep him completely secure while they do the radiotherapy side of it ... It ended up that he hated this, he couldn't stand it to such an extent he went and said, "I will actually stay here completely still, don't put me in the mask." Which is what they did, he went through the rest of his treatments bar the first one without the mask on.



*Figure 2.* A photograph showing the radiation mask used during Andrew's five-year-old son Alex's radiation treatment.

The tangible reality of the mask powerfully communicates the implications of Andrew's decision to allow his child to proceed with radiation therapy, and the heavy burden of his role as Decision Maker. This is further reinforced by Andrew's detailed recollection of his son's treatment, which suggests that as a Decision Maker, Andrew was watching over his son and felt invested in the outcome of his decision for the radiation treatment to go ahead.

When in the role of Decision Maker, fathers realised that with greater control comes greater responsibility and that decisions about what was in their child's best interests were not always clear cut. It is clear that decision-making, while affording fathers a sense of control, is not free of the uncertainty or the weight of responsibility surrounding cancer treatment (Hiles & Cermak, 2008) and that many fathers struggled with this reality.

### **Active Advocate**

Fathers described adopting the role of Active Advocate for their sick child as another way of regaining some control over their child's situation and increasing the extent to which they felt useful as a Cancer Dad. After the initial stages of shock and feeling helpless, fathers felt driven to seek more detailed information about their child's illness and treatment regime. According to Cayse's (1994) study, gathering information is one of the most common strategies for parents of children with chronic illnesses. Fathers of children with cancer felt that this was a way to exercise some control over their child's situation and to protect their child from any unnecessary procedures or side-effects. One father, Dan, described the importance of becoming well-researched about his daughter's cancer:

Information is power, knowledge is power, and so we wanted to know everything and did lots of looking into it. *Dan*

By finding out information, fathers could become more confident and involved in medical decisions regarding their child's treatment. Holm, Patterson, and Gurney (2003b) reported a belief by parents of children with cancer that being well informed on medical issues was essential to being an effective advocate for their child. It is clear that Dan similarly views the accumulation of medical knowledge as an increase in his "power" as an Active Advocate for his daughter. Dan's search for information is a reaction to the powerlessness and uncertainty which overwhelmed him during his initial role as a Cancer Dad. It is evident that embodying the role of Active Advocate was important to fathers, particularly in the medical setting:

We were very well researched and then even more so when they give her the fatal dose of chemotherapy. I don't want to sound like I'm bagging the nurses 'cause they're absolutely outstanding, they run the place up there, they'd be stuffed without them, but the nurse got too busy and didn't come in and start giving the antidote and missed the thing by six hours or something. After that we knew what was coming up and if they weren't there within five minutes we'd go and find them and say, "She needs this now," or, "She's due this". We were right on top of things. *Dan*

The parents know more about it than anyone else. You learn things like all the different types of chemo. And some days they forget chemo. You go for spinal chemo and you go back to the ward, they go "You can go home now". "You've forgotten to give him his chemo in the blood". "Oh". Changed shifts and all that sort of stuff. So we're the ones who keep it on track. If it wasn't for the parents we'd be screwed really. *Ryan*

These fathers communicated the urgency of their role as a "very well researched" advocate for their child by explaining the responsibility they took upon themselves to monitor their child's medication and treatment. Researching and ensuring the correct protocol was followed for treatment were ways in which fathers could take practical action and feel like they were a vital part of their child's battle with cancer. Fathers were able to acknowledge that sometimes nurses were "too busy" and had a number of patients to oversee, while as a father their sole focus was the wellbeing of their son or daughter. By recognising their role as an advocate and an expert on their child's health, fathers were able to keep their child's medication on track and oversee their procedures. Fathers were also active in advocating for their child by seeking additional medical help and ensuring that their child received the appropriate medical care and attention:

I think it was the neurologist who I saw, so I grabbed him, and I'd been trying to get hold of him. I said I need to see you, can you go up now. We went up the ward and he prescribed an anti-seizure epilepsy drug, which is good for headaches, and we haven't had a headache since. *Ryan*

Ryan portrays his story as one of success – he actively engaged a specialist and as a result, his son no longer suffered from severe headaches. In this way, taking control of the situation in the role of an Active Advocate is positioned as positive. The way in which Ryan uses commanding and assertive language communicates the urgency he feels, and the drive to protect and advocate for his son – he "grabbed" the

neurologist and said “I need to see you... now”. By taking control into his own hands, Ryan is able to regain a sense of confidence in his role as an advocate for his son’s battle with cancer. Jones and Neil-Urban (2003) also investigated the experiences of fathers of children with cancer and found that standing up to doctors about medical issues relating to their child was a constructive way of regaining a sense of control and regarded as a satisfying experience. Other fathers, such as Robert, also described the importance of standing up to the doctors and being involved in decisions about his daughter’s treatment:

And I wasn’t a doctor, I just wanted to make sure she was going through and having the best potential positive outcome. And that’s every father’s or mother’s right to do that as well, to question. And I don’t think I was wrong too many times, they actually changed a few things. And that wasn’t a pissing match, who can piss the furthest, it was more that we were in that situation and I wanted to make sure that you guys were on your game, that’s all: the medicines, and the outcomes, and the side effects. About the weight thing, they wanted to put a tube down her throat and she was very raw. And I said if you do that, it could lead to an infection, which could lead to larger things. I know her body and she hasn’t lost any weight. In the end, they said “that’s your call, you know what you’re talking about, you know your daughter”. *Robert*

Robert describes being assertive and confrontational in his role as an Active Advocate for his daughter by making sure that the medical team were on their “game” and using his “right” to “question” medical decisions. However, he clarifies that he did not take on this role for egotistical reasons: it wasn’t a “pissing match”. Instead, Robert realised his unique role and the importance of his expert knowledge of his daughter in informing and improving decisions about her care. Clarke and Fletcher (2005) also reported that parents felt they had to be assertive, and even aggressive advocates at times, to ensure that their child received appropriate treatment. Fathers actively involved themselves to ensure that their child had the “best potential positive outcome”. Again, the story of Active Advocate is portrayed as one of success: Robert reports that he “wasn’t wrong too many times” and that his advocacy resulted in a few changes in his daughter’s medical care. However it is also clear that these father-informed changes come with a shift in responsibility from the medical team to the father, as they acknowledge his expertise and right to make decisions on his daughter’s behalf. Caleb reported a similar experience in the role of Active Advocate, in which he believed that

his pervasive knowledge of his daughter and her behaviour across a number of different situations, should override medical recommendations:

They wanted to put her on – I can't remember the name of the drug – basically anti-depressants but they would've been on that for the next two years. We said, "You see her for 10 minutes, you see her for an hour when she's here. The rest of the day she's fine, she just doesn't like needles so we're not going to put her on drugs to make your life easier for the hour that you have her so, I'm sorry, but no". We held our ground fairly firmly on that. We've taken the advice on everything apart from that and we just said, "No".

*Caleb*

While medical staff recommended that Caleb's daughter should be put on medication to help with her anxiety, Caleb stood his ground as he believed that the anxiety was triggered by needles and did not extend to other areas of her life. It is evident that fathers sometimes feel that their knowledge of their son or daughter can be more important than the medical expertise of professionals in making key health decisions. Clarke and Fletcher's (2003) study supported this idea by reporting that parents realised their responsibility to function as advocates for their child and perceived themselves as experts of their own child. In the role of Active Advocate, fathers are able to acknowledge the importance of their expertise regarding their child and to re-establish a sense of control by standing up to doctors and ensuring collaborative decisions that have their child's best interests at heart. A father's expertise can be particularly valuable when his son or daughter is feeling distressed and vulnerable due to the invasive nature of cancer treatment.

The realisation of their child's vulnerability and need for advocacy during cancer treatment also caused fathers to act in a protective manner in public settings. Several fathers brought along their child's beads of courage to the interview, a string of beads which symbolised each component of treatment undergone, as well as special challenges and milestones along the way. These beads were used by fathers as a narrative device to shape stories about the journey their child had been on, and to construct different roles they assumed along the way:

His beads would actually go around this room. Huge. That's how many chemical interventions he's had over the years ... we strung them all up and they snapped - it was that heavy. We needed a massive piece of fishing wire to get them on there. *Jack*



When we show these to people, it's very moving for them, because they can actually see it tells a story ... we felt it was the best way to remember things. *James*

For Jack, bringing the “huge” string of his child’s beads of courage (see Figure 3) along to his interviews was an effective means of communicating to the researcher and audience the duration and extent of his son’s treatment. James recognised the significance of his child’s beads of courage as a narrative device that was able to uniquely tell his daughter’s story to other people, as well as acting as a visual reminder for his own family of all they had been through together. For each of these fathers, the beads were a means of sharing with the audience a visual representation of the sheer number of interventions their child had experienced throughout cancer treatment, which in turn gave a sense of authenticity to the challenges and struggles they conveyed throughout their narratives.

The beads of courage were also used by several fathers as narrative tools to draw attention to and focus on particular milestones or challenges during their child’s cancer journey, such as their child’s loss of hair as a side effect of treatment. Max was



*Figure 3.* A photograph showing Jack’s son Matthew’s beads of courage as a symbolic representation of his journey through cancer treatment, and Jack’s journey alongside him.

one of the fathers who pointed out a special bead in the shape of a face, which symbolised his daughter's hair loss and the challenges surrounding this event (see Figure 4). For some fathers, the loss of hair was much more than just a physical side effect, as it marked a dramatic change in their child's appearance and served as a public marker of their disease:

And when she had no hair and she was wearing a bandana and she would walk down the street looking like that, and ... complete strangers, some would know and they'd give us a smile and a nod, but that's human nature, I know that. Others would just, oh, interesting thing in the window. It was very obvious. We got to a point we would just laugh about it. What else can you do? It's either that or you cry. You can't do that. *Max*



*Figure 4.* A photograph showing Max's daughter Hillary's beads of courage, which are a symbolic representation of her journey through child cancer, and Max's journey alongside her. A bead in the form of a face, signifying hair loss, can be seen in the top central region of the photograph.

That was always hard to take him out for a walk, people looking. He was like this little bald-headed extra-terrestrial running around. *Jack*

Fathers struggled with the physical transformation of their children and the subsequent desire to advocate for their child and somehow protect their child from the reaction of strangers. Hair has historically been associated with beauty (Holm et al., 2003), and the loss of hair has been seen to denote a loss of individuality and attractiveness (Tobin & Begley, 2008). In the context of cancer, a child's loss of hair was a powerful visual reminder of their vulnerability and need for an advocate. Not only must fathers do their best to advocate for their child within medical settings, but they must also grapple with the difficulty of protecting their child from the stares and reactions of strangers in public settings. This provides a difficult challenge for fathers in the role of Active Advocate – realistically, they are unable to control the reactions of strangers. While there is a sense of sadness at the loss of their child's hair and health, all a father can do is to try to transform the situation into one to laugh at – “what else can you do? It's either that or you cry. You can't do that”. Thus, while there were some success stories conveyed in the role of Active Advocate, there were also some challenging areas in which fathers were unable to control or influence their child's situation.

### **Practical Policeman**

A third role through which fathers attempted to re-establish a sense of control was that of Practical Policeman. This role involved taking charge of practical areas of family life and ensuring that infection prevention protocol was carried out and that the sick child underwent their medical procedures. Fathers such as Jack described gravitating towards practical ways of helping out and taking charge:

And you're always the Dad in many ways, but it was deciding to be the practical Dad and sort all the problems that arise. Whereas my wife is more emotional about things, I tend to be more practical, that's probably how I deal with things. *Jack*

Jack decided to assume a practical role in caring for his son and to focus on logistics as a means of dealing with the reality of his son's cancer. Jack's assertion that he is more practical, while his wife is more emotional, is consistent with traditional ideas about masculinity. Historically, male gender identity has been linked to instrumental rather than expressive coping styles (Parsons & Bales, 1955). This suggests that fathers may perceive more active methods of coping (such as providing practical help and problem



solving for his family) as more masculine than expressive styles of coping (such as seeking support from friends or offering emotional support to his family). Another father, James, also emphasised the practical tasks he took upon himself during his daughter's treatment. James brought along a box of his daughter's oral chemotherapy medications (see Figure 5) to his interview as a narrative device to represent one aspect of his role as a Practical Policeman: helping his daughter to manage her medication. Seeing the multitude of empty containers is confronting and James uses this to provide the interviewer and audience with a sense of the overwhelming nature of his task, and the importance of his role in taking care of his daughter's practical needs. It seems evident that practical solutions often became a key focus for fathers, and helped fathers to regain a sense of control and usefulness within the family system.

As a result of information gathering, fathers quickly became aware that their child had a high risk of infection during various points of their chemotherapy regime (due to decreased levels of infection-fighting white blood cells) and that any infections could be serious or even fatal for their child. Consequently, fathers saw the need to be vigilant in the enforcement of hygienic practices and thus minimise their child's risk of infections. This hypervigilance by fathers has been theorised to result from a futile search to discover a definitive cause of their child's cancer (Jones & Neil-Urban, 2003). While fathers were unable to protect their child from the cancer itself, they took it upon



*Figure 5.* A photograph showing empty containers of oral medication, as an illustration of James' practical role in managing his daughter Jessica's medication.

themselves to protect their child from further threats to their health. Fathers constructed the role of Practical Policeman as one in which their key tasks were to minimise the risk of infection by increasing hygiene and education about hygiene, maintaining hypervigilance about exposure to infection-causing bacteria, and protecting their child from people who may pose a threat to their health. One father described taking quick and decisive action to make their family home more hygienic for his son with leukemia:

Whereas I went home the first week and chopped the kitchen to pieces and put a new special fridge in, and organised a new air conditioning system to be put in the house ... we blew 10 grand in the first week ... We're really focused on the healthy eating, because his immune system's compromised. So we put this 5 thousand dollar fridge in the kitchen. And it wouldn't fit so I had to chop the wall down, make it fit. And that was done in three days, all done and installed ... But some people just can't afford that, you know, and they're the ones who are always back in the hospital where they're a lot sicker ... We really focused on cleaning the house, we use steam mops, we don't use any chemicals anymore, we clean the house with baking soda and vinegar, and we put a new air conditioning system in, and we've put in a new air filtration system that filters all the air in our house and all that sort of stuff. *Ryan*

For Ryan, having a safe and hygienic home for his son was a top priority. As a Practical Policeman, he was motivated and willing to invest time and finances in order to remodel the family home. In this way, he could take charge of the physical home environment and feel that he was making a significant difference towards his son's wellbeing and recovery, by minimising his risk of infection. Ryan also described making changes in the way the house was cleaned, in order to reduce the chemicals his son was exposed to. The extent of these changes suggests the intensity of the drive fathers feel to take on the role of Practical Policeman and do something to help and protect their child. Ryan also describes being very protective of his son's contact with other sick children:

We had to go in (to the Emergency Department) only a couple of weeks ago with a high temperature, and we have to find our way through all the parents with their snotty, snivelling kids, who didn't like the fact we got seen first, because we can't be sitting around in the waiting room with the snotting, snivelling kids. And they, a couple of them stood up and tried to stop us from going through, because they'd been there for four hours waiting to see

a doctor, when we got sent straight through. So I just took my son's hat off and showed them he had no hair. They soon moved out of the way.

Ryan clearly portrayed himself as a Practical Policeman who was responsible for monitoring his son's contact with infected people. In this instance, he took quick, assertive action that was perceived as breaking social norms by other parents. Social norms dictate that it is rude to push in front of others who have been waiting longer, however, Ryan is willing to violate those norms: his only concern is protecting his vulnerable son from the "snotting, snivelling kids" who could pass on their infections. He was operating by a different set of rules, designed to protect his son from danger, and took on an authoritative stance to enforce these. Acting as a Practical Policeman was also constructed as a role which involves hypervigilance and education about hygiene:

But what you tend to do is you end up not trusting anybody... You end up becoming a very close knit unit 'because if you let anybody in, you're worried they'll do something that'll cause harm. So they don't wash their hands, they cough, stupid things. They blow their nose or they don't remove their shoes. They don't keep a high standard of hygiene. You worry about all that side of it. *Andrew*

It's quite a shocking thing. People don't understand. You've been in the cancer world. People don't understand how infections affect people, and how easily they transmit it. Our four-year-old is awesome. Every time he comes inside, straight into the bathroom, and spends two minutes busy scrubbing and washing his hands. People come in from outside the hospital, and you tell them to wash their hands. "Why, I'm not dirty?" But you've been touching stuff, in the lift, they just don't understand. *Ryan*

It is clear that hygiene was a significant daily concern for these fathers in the role of Practical Policeman. Medical guidelines for parents of children who are neutropenic (experiencing low levels of neutrophils in the blood, leading to increased susceptibility to infection) include strict hand washing practices, mouth and perianal hygiene, awareness of blood values, and monitoring temperature for signs of a fever (Bryant, 2003). Fathers described their frustration at the lack of consideration displayed by others: "people don't understand" and they "don't keep a high standard of hygiene". Due to this lack of understanding, fathers felt a heightened sense of isolation. It is clear that their family life is different, their behaviours and hygiene are different; they are no longer a part of normal life, as they live in the "cancer world". This sense of separation

from “other” people leads to a mistrust in those from “outside” their immediate family and the cancer world. There is always the fear that they, as the Practical Policeman, will let their guard slip and someone else will “do something that will cause harm”. The fear, worry and isolation characteristic of the role of Practical Policeman also drove several fathers to restrict social interactions:

Initially, you can't really go anywhere; you're just scared to take your kid anywhere. Well why would I take him over when your kid's got a stinking cold? So he basically missed the first two years of education because he got diagnosed at 5. And if you did, you had to ask this long list. Look if your kid's got a cold, have they had chicken pox, have they had this, have they had that, and who wants somebody in their house like that? He couldn't go out, so we couldn't go out. The whole world becomes a bacterial infective place, you know. That's the practical side of me, saying, I'd have to think about that stuff. It's like you're living in a bubble. Everybody comes to the outside, and we keep them on the doorstep until you've checked all them out. *Jack*

Had a sign on the door, “Sorry, Charlotte's sick, you can't come”. Our younger son couldn't have friends over; we didn't have people over at all. She couldn't go anywhere. When we thought she was getting well and you get brave every now and again, have someone over, have a friend of hers over. You'd be scanning them when they came in and checking them out, making sure they're well. When they walk in the door, if they sniff you'd push them back out and, “see you later”. *Dan*

After a diagnosis of cancer in a child, Woodgate (2006) argues that there is a sense in families that the world has changed – it is no longer as secure or safe. Accordingly, fathers felt like they needed to create a safe “bubble” to separate and protect their child from the unsafe and uncertain “outside” world. Both Jack and Dan described the family home as part of this protected zone when their son or daughter was home from hospital. As such, the doorstep was the gateway to this protected zone and the place in which they, as the Practical Policeman, would vigilantly “check,” “scan,” and cross-examine prospective visitors for any signs of illness. It is clear that these two fathers felt a great sense of responsibility to protect their child from infections, and to stand in the gateway between them and potential threats. Only when their child was perceived to be well enough, did fathers such as Dan feel “brave” enough to allow a friend over for a visit. Even after a friend was initially approved, Dan described remaining vigilant in the role of Practical Policeman and being ready to send



them away if they even sniffed. Dan brought a box of his daughter's medical bands and her portacath (see Figure 6) along to his interview, and used this as a narrative device to lend credibility to his account and provide a visual reminder of the need for caution and vigilance around the threat of infection:

These are all Charlotte's hospital bands. I know her hospital number. I'll never forget that. This here is a portacath ... Charlotte had four or five because she got infections in a couple of them, one didn't work, so they had to take them out and replace them. This is our friend who worked very well because every time you go in to start your chemo they access it and have to get blood out of it ... That was a massive part of her getting her chemo was getting the portacath that worked and the two times that she got the infections, they thought it was in the port.

Dan uses a box of his daughter's hospital bands and a description of his daughter's fourth or fifth portacath as their "friend" to provide a compelling illustration of the need for caution and the consequences of infection. Charlotte's chemotherapy treatment was dependent upon having a portacath that worked and was infection-free, and as the Practical Policeman, Dan wanted to ensure that his daughter had the best chance possible of staying free from infections.



*Figure 6.* A photograph showing a portacath and box of hospital bands belonging to Dan's daughter Charlotte.

Fear of infections restricted social outings and relationships for both the child and the broader family unit, as the “whole world becomes a bacterial infective place”. Education around the risks of bacterial infection for a child with cancer meant that fathers often chose to restrict the people and places that their entire family had contact with: “he couldn’t go out, so we couldn’t go out”. Other studies have similarly reported that a child with cancer’s susceptibility towards infections can be experienced as a disruption to family life and that parents often restricted activities for the entire family, especially indoor activities involving lots of people, such as an outing to the swimming pool or children’s parties (Björk, Wiebe, & Hallström, 2009). While most fathers erred on the side of caution and tightly monitored their child’s visitors, one father described his decision to take more risks in this area for the sake of his daughter’s childhood:

If we got a day out of hospital, it was great. Picked up infections, we kind of knew, it’s going to happen. But don’t put her in a glass ball. If she gets a day to go home, go home. If she gets an infection, go back to hospital and deal with it. But you can’t put her in a glass house and treat her like that. Because a child has a right to be a child still. And we got bit a few times, but I think Emma was happy to come home... She loved being home, but then we again walked as much as we could, get some fresh air into her, went down to the beach ... Got her to the mall. All girls love shopping, it doesn’t matter what age they are. It was a risk we took; she could have picked something up. But we looked at her blood values, so we knew that her body wasn’t the best but she could fight off a normal cold. So we just planned it, 10.30 on the Monday, the chances of the mall being packed is pretty small. We went and did that quite often. *Robert*

Robert challenged the idea that the best thing for a child with cancer is to be kept inside a “bubble” or a “glass ball”. It is clear that he strongly values allowing his daughter to come home and take part in normal life as much as possible, as a “child has a right to be a child still”. Robert points out the inevitability of infections and argues that strict infection control can inhibit the experience of a normal childhood, and severely restrict the opportunity to go on fun outings and interact with friends. He describes how he took a calculated risk, based on Emma’s “blood values”, to allow her an outing to the mall outside of peak times as “all girls love shopping”. Robert’s decisions about his daughter are consistent with findings by Björk et al. (2009) suggesting that as parents of children with cancer became increasingly familiar with the interpretation of their child’s blood values, they were more confident in allowing the child to engage with more activities when the blood values were high. While it is

evident that Robert does still encourage some infection control, and will only take informed risks, it seems that on certain occasions, he sees his role as Practical Policeman as secondary to his role as a protector of Emma's childhood. Robert constructs his role as Practical Policeman as a complex role, where he feels the tension between salvaging what he can of his daughter's childhood and of protecting her from the risk of infections.

In this way we learn that while many fathers may present a role as more simplistic and straightforward, other fathers may construct a more complex version of the role based on their unique values and experiences as a father. It is interesting to note that out of all the fathers interviewed, Robert was the only father whose child had relapsed and was being treated for leukemia a second time. It is possible that his familiarity with the processes and protocols of cancer treatment, and his past experiences, may have alleviated some of his fears around the potential risk of infections. It also seems understandable that if his daughter had spent several years of her childhood undergoing treatment in the past, that Robert would feel more protective of the remaining years of her childhood as she underwent treatment for the second time.

While some fathers were variable in their attitudes towards infection control, most fathers were consistent in describing the enforcement of treatment for their child as the most difficult and challenging part of their role as Practical Policeman. When their child refused to undergo a medical procedure, such as intramuscular chemotherapy injections, fathers were often relied upon to hold their child down so they could receive treatment:

He had these injections in his leg, and as the Dad, I was the one to go on with it really. Because my wife couldn't, she's not one to stand there. And I was. Because I turned all that emotion off, I suppose, just get him to do it. And he used to sit on me, used to hold him still while they stuck these things in his thigh and they're really painful, must admit they were. But it's the only way you could do for him. *Jack*

In our mind, there was no alternative. We said to her, "The alternative to your treatment is you'll die, so, you're going to have your treatment or you're going to die and we're not going to let you die so you're going to have your treatment". I came in and my role was to hold her down and to pin her down. Over time, what that meant was that she knew it was no point resisting because I was stronger than her where she could out-wriggle her

Mum. I was concerned about the impact on the relationship that would have but my primary concern was keeping her alive and I figured, well, if it impacts our relationship I'd rather have a bad relationship with someone that's alive than a good one with someone who's dead. That was an easy decision to make. *Caleb*

Jack and Caleb both describe the difficult experience of holding down their child during treatment. While fathers described this as one of the hardest struggles and lowest points of their role as a protector of the sick, they each made a point of justifying their actions and emphasising the inevitability of the decision to forcibly restrain their child. Jack defended the necessity of his actions by claiming that it was the “only way” that his son would receive the prescribed leg injections. He describes “turning all that emotion off” so he could perform the job he needed to do as his son's father. Caleb outlines a logical argument to support his conclusion that there was no other choice – his “primary concern” was to “keep her alive” and holding or pinning her down to receive treatment was a necessary step in achieving this goal. Caleb does consider the impact that his actions as a father might have on their relationship in the future, but he decides that a “bad relationship with someone's that alive” is preferable to a “good one with someone who's dead”. Nicholas et al. (2009) found that fathers struggled with role confusion as their previous expectations of their role as a man and father were challenged by the uncertainty of their child's health and long-term outcomes. In their role as Practical Policeman, fathers had to fight feelings of failure and suppress the desire to protect their child from short-term pain in the hope that their child would make long-term gains. Fathers had to evaluate their use of control and reconcile this with the conflicting emotions they were experiencing:

To take control of the situation, when he was having problems with having those injections in his leg. I think that's what it takes to be a father, to make that decision, to take, to take control of something that he can't take control of himself. And doing that for the right purpose, made me realise that yes, I'm right; I'm doing this for your best interests. Instead of standing there, instead of being a wishy-washy Dad “Oh, yeah, ok, son” I said “No, come on, we're going to do it”. I think you change that relationship. Made him realise that I was his Dad. I needed to make the decision for him. That, once they solidified it, it actually made me realise that that's what Dad's do. *Jack*

Although it was very difficult and challenging part of the cancer journey with their child, some fathers were able to recognise the importance of their role as a Practical Policeman and Cancer Dad. Jack also makes it clear that his intention was not to

assert dominance or authority over his son, but to provide supportive strength and a sense of conquering fears together: “we’re going to do it”. His job as a Dad was to “take control” when his son “can’t take control of himself” and to stand firm in what was best for his child. In the end, many fathers realised that a key characteristic of being a Practical Policeman was the ability to set aside their own emotions and fears, to act in their child’s best interests in the long-term.

## **Summary**

This chapter explored the shock and devastation which fathers experienced when their child was diagnosed with cancer, and the ways in which they re-evaluated their roles and identity when they realised that they were now a Cancer Dad. Following the uncertainty and chaos of diagnosis, fathers took on the roles of Decision Maker, Active Advocate, and Practical Policeman in order to regain some control over their child’s situation and to feel that they were making a difference for their child and family. In the role of Decision Maker, fathers grappled with complex and difficult decisions, while in the role of Active Advocate, fathers became aware of the vulnerability of their child and the importance of being assertive and well-researched in order to stand up for their child. Finally, in the role of Practical Policeman, fathers faced the challenging tasks of enforcing infection control and holding their child down for treatment procedures.

## Chapter Four

### Cancer Dad and Finding Strength

This chapter continues with an exploration of the ways in which the broad, overarching role of Cancer Dad manifests through secondary roles, this time centring on the idea of finding strength. Alongside taking control, one of the key priorities for fathers following diagnosis was to find the emotional strength they needed to sustain themselves as well as to support their family throughout the often lengthy process of cancer treatment. This idea of finding strength in the role of Cancer Dad is explored through discussions of the secondary roles of Emotional Rock and Lone Wolf.

#### Finding Strength

##### Emotional Rock

Following the shock of their child's diagnosis with cancer, fathers often became acutely aware of the need to find the strength to support their child and their family through the ups and downs of treatment. In particular, fathers became mindful of their family's emotional needs and reported feeling pressured by expectations from their family and those around them to take on the role of Emotional Rock and provide emotional stability for their family:

You're expected to be the emotional rock. But I'm probably the more emotional one. *James*

James challenges the idea that he should be the practical, stable parent. While he recognises his own tendencies towards acting emotionally, James still feels expectations from those around him to be "the emotional rock" of the family and to handle stressful situations without showing his emotions. Emotional stoicism is perceived to be one of the central characteristics of Western masculinity (Brannon, 1976; Jansz, 2000), and fathers such as James report acute awareness that society values men who restrict their emotional expression and appear in control. His personal challenge to stereotypes suggests that not all fathers fit into the traditional mould of preferring to manage difficult situations in a practical, non-emotional way, and the expectation to do so can place an unnecessary burden on fathers who do not conform to gender stereotypes.

However, most other fathers did align themselves with characteristics consistent with the role of Emotional Rock:

My wife will be more inclined to be emotional about it ... I approached it very, I suppose, technically – step one, step two, step three. *Owen*

My wife was much more emotive than I am ... I don't know how other males think about it but I felt like I didn't need to emote. That's what I was, that's what I said around more practical situations - it was more about dealing with the issue. *Jack*

Fathers described managing their child's treatment more "technically" than their wives and focusing on "practical situations". Furthermore, Jack describes feeling like he does not need to display his emotions in front of others. This is consistent with constructions of masculine behaviour which involve the concealment of emotions which may imply vulnerability or dependency (Seidler, 1997). Playing the role of Emotional Rock was seen by Jack as a necessary part of being a Cancer Dad and helping his family to get through cancer treatment:

Could feel upset, but couldn't do it in front of people. Don't know why. I thought that if I did that, I felt like I wasn't supporting them in some way. Sounds stupid. Maybe it was wrong, don't know really. But you just do what you do, as a course of action. But what more can you do, what sort of emotions do you share when your kid's sick? Can't go round all the time crying and all that. You know, if I'd been the emotive type, how would he have got those injections in his leg? What would they have done to him?  
*Jack*

Fathers commonly held the perception that in order to fully support their family, they needed to be an Emotional Rock, pushing aside their own emotions and offering strength and stability for their family. While expressing emotions in such a stressful situation can be readily accepted in women and children, men are traditionally expected to exert control over the expression of their emotions (Seidler, 1997; Walton, Coyle, & Lyons, 2004). Furthermore, Jack provides a practical rationale for hiding his emotions and getting on with a "course of action" – certain situations, such as holding down his child for injections, required someone to sacrifice their emotions for the sake of the child. In society, men are often expected to bury their intense emotions during stressful situations in order to provide strength and leadership to those around them (Chesler & Parry, 2001; Neil-Urban & Jones, 2002a). However, fathers may struggle to carry this burden of trying to remain in control during the difficult and emotionally-



charged period of cancer treatment. A number of other fathers described feeling driven to hide their own emotional turmoil in order to protect their sick child:

You've got to be strong, as strong as you possibly can be. You're one of the lynch pins of the family and you can put on a brave face as well at times. *David*

Recovering quickly from bouts of sadness or being scared or whatever because you can't let it show, you can't let her know. *Dan*

The father can have a significant and influential role as one of the "lynch pins" of the family. This image of a lynch pin, the piece of metal used to keep a wheel from falling off, is used powerfully to emphasise how David feels about his role in the family. He sees himself as an Emotional Rock, holding his family together at the centre during cancer treatment, and he feels it is his responsibility to keep the wheel in place, to provide stability for his family. David feels that the wellbeing of his family hinges on his ability to be "strong" throughout his daughter's treatment for cancer. It seems evident that for some fathers, being "strong" for their family can mean masking or hiding their own suffering so that it does not distress their child further. Dan conveys a sense of urgency – he has to "recover quickly" from times in which he feels sad or scared as he "can't let it show" in front of his daughter. Childhood is often socially constructed as a time of innocence, dependency and incompetence (Young et al., 2002) and in the context of childhood cancer, it is understandable that fathers would perceive their child as even more vulnerable and in need of protection. Protecting their child may at times mean that they need to put aside their own emotions in order to provide support and assurance for their family. These ideas are supported by Nicholas et al. (2000) who argued that fathers perceived that their role during crisis was to provide strength and equilibrium for their family, and that taking on this role would at times require suppression of negative emotions in front of their partner and children.

However, many fathers struggled to contain the intensity of their emotions, or to feel like they were providing their child with adequate support and strength, when faced with the traumatic experiences of treatment. Watching their child suffer and feeling powerless provided a significant challenge to fathers in their role as Emotional Rock:

Just seeing her going through it, knowing that it hurts, and knowing that she's not well. The thought of her dying, that's always there, it's always in the background but that's not as bad as watching your child scream when she's getting two big needles stuck into her, intramuscular thigh injection, and you can't do anything about it. *Dan*

It's just a nightmare. And the kid gets quite a lot of anxiety. He hates his port being accessed. He has a portacath in his chest. In weeks gone by he's been having massive, massive anxiety. Vomiting beforehand from the anxiety, crying, he'll start counting from 20 down to 0 and back to 20 before they put it in. That's him trying to delay it, a delaying tactic. It's just very traumatic. *Ryan*

The most telling point was when he's there and he's drained and he's completely and utterly ... he's just gone through one lot of chemo and he just looks at you. This is a child you've just watched him grow up and everything else, in your eyes they're still a baby and he turns round and he goes, "This isn't fun anymore". You can't say anything to that, there's absolutely nothing you can say and you still know he's got months to go in his treatment. You still know he's got to go through a whole load of more pain and agony and everything else. *Andrew*

Each father shared stories that attempted to convey the depth of suffering their child experienced as a result of cancer treatment, and the extent to which this challenged their role as an Emotional Rock. Seeing their child "scream" in pain, "vomiting beforehand from anxiety", or completely and utterly "drained" as a result of chemotherapy treatment and feeling like there was "absolutely nothing" they could say or do to ease their child's distress was a disempowering experience for these fathers. The helplessness experienced by Andrew is also highlighted as he perceives his son as still a "baby", a vulnerable child he watched growing up; a child he now cannot protect from further "pain and agony". The reminder of Andrew's history with his son is powerful in expressing his grief over his son's diagnosis and what his son must continue to go through. However, it is clear that this expression of emotion is only for the listener: Andrew is silent and feels unable to communicate his sense of grief and powerlessness to his son. When assuming the role of Emotional Rock, fathers felt unwilling to grieve alongside their children, or to offer them false reassurance; instead, they were compelled to put on a brave face.

Fathers also used their child's beads of courage to tell stories of suffering and hard times during treatment. While the stories focused on particular hardships, they were also bound up with fathers' recognition of their child's bravery and courage in the past and hope that their child would also overcome challenges in the future. James pointed out the black beads in his daughter Jessica's string of beads (see Figure 7), which represented the injections she had received, and explained how proud he was of her bravery in this area:



*Figure 7.* A photograph showing James' daughter Jessica's beads of courage as a representation of her bravery during injections (represented by black beads).

I was quite proud of the way she handled her treatments. Her injections consisted of a needle in each leg as close to the bone as they could get. She didn't even flinch for that and was quite proud of her for that. I think the nurses were probably more shocked themselves. *James*

The black beads in Jessica's beads of courage are utilised by James as a narrative device which conveys to the interviewer and audience how many injections Jessica has endured and the bravery with which she has endured them. For James, these black beads evoked a strong sense of pride in his daughter's resiliency, and reminded him of the way he was empowered in his role of Emotional Rock by his daughter's own strength, enriching his narrative.

Several other fathers also used their child's beads of courage to tell stories about the challenges their child had overcome:

The bigger beads are courage, brave. They all mean different things ... he had surgery and they pulled out all his baby teeth. Must have had about seven they had to pull out. *Luke*

Special medical challenges ... all these big fancy beads. This one was one of her first bad side effects you could say. It's a bit of a funny one in some ways. With one of the chemotherapy drugs, she got terribly constipated and she was going, everything seemed to be right, is what we thought, but in actual fact what was happening is we found out from the x-ray is we have what, seven and a half metres of intestine? She was completely full. Complete. The whole lot. And on the x-ray it showed that. So when Hillary saw that challenge bead she picked it, obviously. We were in hospital for a whole week, seven days thereabouts for it, because they couldn't do it from the back end, they had to go from the top end. And that's just one of many challenges that she's had. They're all here somewhere. This is really what we hold on to ourselves. *Max*

Each challenge bead served as a trigger for a story of what the child had overcome, and it is through these stories that we hear of the child's courage, bravery, and resilience through the eyes of their father. Woodgate and Degner (2005) reported a similar narrative idea expressed by mothers of children with cancer who found great personal strength in their child's spirit and the depth of courage they displayed during treatment. They argued that the cancer experience was made more tolerable for mothers when their child was able to maintain spirit in the face of adversity (Clarke & Fletcher, 2005). Similarly, in future crises, fathers stated that they can hold on to the memories of what their child has accomplished already and hope that they will pull through again. It may be that fathers reframe narratives of hardship as "milestones" to hang on to in order to feel hopeful about the future and to make their current experiences of cancer more tolerable. Furthermore, memories of their child's strength and resilience during painful aspects of treatment can evoke pride in fathers and become a source of personal strength as they undergo their own challenges and hardships as a father of a child with cancer.

The mental strain and trauma felt by fathers who must watch their child undergo painful cancer treatments is reflected in studies looking at the rate of post-traumatic stress symptoms in fathers of healthy children in comparison to children with cancer

(Barakat, Alderfer, & Kazak, 2006). According to a recent study focusing on parents of children with cancer (Kazak et al., 2005), all but one parent in their sample reported at least mild post-traumatic stress symptoms, and of the fathers, 57% reported post-traumatic stress symptoms within the moderate-severe range. Kazak and colleagues (2005) also argued that there was a significantly higher rate of intrusive thoughts, arousal, and overall post-traumatic stress symptoms for fathers of children who were currently undergoing treatment, in comparison to fathers in an off-treatment group. These findings suggest that fathers carry a tremendous burden during their child's cancer treatment and may pay a significant price when they choose to suppress their emotions rather than seeking to process them in a healthy way.

The role of Emotional Rock is a challenging role for fathers to perform in the face of their child's suffering. Cancer Dads feel caught between the need to provide strength and protect their families by controlling their own emotional expression, and the need to acknowledge and manage the reality of their own emotional trauma. One of a father's strongest instincts is to protect his child and family from emotional pain, but many fathers may not consider the cost of doing so and the importance of also attending to their own emotional needs. Findings of the current study suggest that it is easy for fathers to become overwhelmed when faced with the suffering of their child, but that fathers may be able to find emotional strength by focusing on the challenges that their child has overcome and taking pride in their child's resilience.

### **Lone Wolf**

During the emotional challenges of cancer treatment, many fathers felt isolated from those around them and did not seek social support. By adopting the role of Lone Wolf, fathers had to learn to be self-sufficient and use their own inner strength and resources to get through hard times. Fathers also experienced a sense of separation from families who were unaffected by cancer:

A lot of support in there for the mothers, but the fathers tend to be like lone wolves around the place. The people who go through that place, there's only those people who understand it, you know. *Jack*

The term "lone wolf" is commonly used to refer to someone who prefers to work alone, rather than with others or in a team (Dixon, Gassenheimer, & Barr, 2003). Jack used this image of a "lone wolf" to convey the sense of isolation he felt as a Cancer Dad. As a Lone Wolf, he was separated from the pack – friends and acquaintances from before his son's diagnosis did not understand what he was going through – and he felt



disconnected from those around him. Cancer Dads also observed that mothers found supports within the hospital, but felt emotionally unable or unwilling to access these supports for themselves. This was further evident in the way in which fathers chose objects which were significant in representing support given to their child, rather than support for their own emotional journey. Luke brought a poster (see Figure 8) to his interview, and used this as a narrative device to represent the support which was offered to his youngest son:

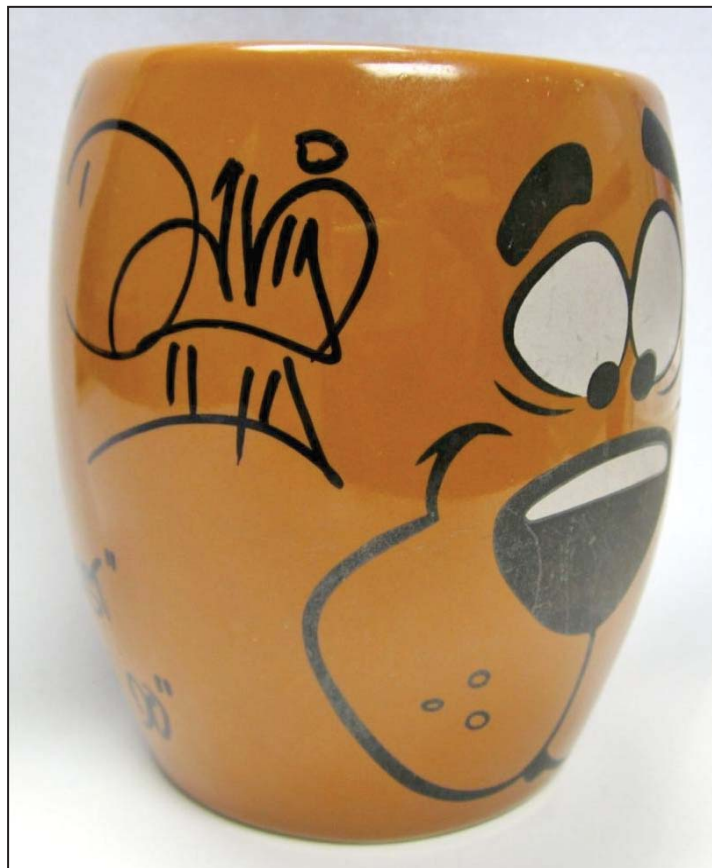
With that poster, that was actually Ryan's pre-school ... his brother was at the pre-school when Ryan went into hospital and then the pre-school made a poster for Ryan.



Figure 8. A photograph showing a poster made for Luke's son Ryan as a sign of support from his pre-school.

Similarly, Jack brought along a mug (see Figure 9) that was treasured by his son to represent the support offered to his son:

The mug. That's a really significant mug. That mug was the day he had to go in for some treatment, and Saturday, he felt sick ... Anyway I took him down to the ward and he sat there with his video. Next thing David Tua (a Samoan New Zealander former professional boxer) walked in the ward ... So he came on the ward, and we were sitting in the treatment room, and he came. I went and introduced Matthew to him. He said "What are you doing Matthew?" and he goes "Oh I'm just watching Scooby doo on the video." He goes "Do you like Scooby Doo?" David goes "Oh yeah, I love him too, he's my favourite. One of my favourite presents when I was a kid was a mug, a Scooby Doo mug." He said, "Do you want it?" "Oh yeah, absolutely, I'd like that." So he stayed for a few minutes. About two weeks later, that arrived on the doorstep. It wasn't the mug, I thought, it was what he wrote on it: "Tough times don't last, but tough guys like you do." ... It goes on his bedroom chest and drawers, it's his pride and joy ... So that means a lot, I think, the saying and the spirit it was given in.



*Figure 9.* A photograph showing a mug signed by David Tua and given to Jack's son Matthew as a sign of support.



This mug was seen as particularly significant by Jack, as it was symbolic of how a stranger had reached out to support, encourage, and uplift his son. By bringing the mug along to his interview, Jack invites the interviewer and audience to share in his narrative and his appreciation of the kindness of a stranger. As Jack tells the story, he focuses on his son's reaction to the gift, and the way his son treasures it as his "pride and joy". Jack is moved at the "spirit" the gift was given in, and is grateful and accepting of the support offered to his son, in contrast to his own sense of separation and isolation as a "lone wolf" who is not understood. The mug becomes a powerful narrative device which prompts Jack's heartfelt account and indicates to the audience that a simple gesture can make a world of difference for a Lone Wolf and his son.

Other fathers also struggled with a loss of social support from networks outside the hospital:

Because like you lose all your friends, you know. For our example, our neighbour that's got a young kid, it's their first child, won't even let their child come into our house in case their child gets cancer. You know, you can't catch it that way. But they're just like, "Can you just throw that over the fence for us", won't even come around. All your friends ... they start off really good, everyone wants to help, and then haven't seen them after about a month. So you rely on your connections you make with the cancer parents. *Ryan*

But it's amazing how some friendships, some people have gone the other way as in they don't want to know us. There's been a few, as in I can count them on three fingers, that have gone completely the other way – don't want to know, don't want to make contact. Whether they're scared they're going to get it or we're contagious, I dunno. Or can't deal with it. I would say that's what it is; they just don't know how to deal with it. *Max*

The pain of losing friends through perceived misunderstandings about the nature of cancer added to fathers' isolation and identification with the role of Lone Wolf. Fathers often felt let down by friends who withdrew as a result of misguided fears that their own child would contract cancer, or because they felt unwilling or unable to deal with another family's tragedy. Fathers also commonly experienced a loss of social support from friends who were initially keen to help but then drifted away. This further cemented their sense of social and emotional disconnection and the idea that others did not understand what they were going through as Cancer Dads. These Lone Wolf experiences of lessening support from friends over time and feeling of alienation are

consistent with findings reported in other studies focusing on fathers (Nicholas et al., 2009; Ware & Raval, 2007). Other fathers similarly reported experiences of social isolation and a lack of friends to reach out to:

There was nobody, really. For me, there was nobody to talk to, to actually really talk about what your fears are, what you're concerned about, what you think is going to happen, how can you cope. *Andrew*

I think we became quite insular around our own house, and we didn't see a lot of other people. 'Cause we just couldn't just deal with socialising, and this whole thing of going, everyone else's lives are normal and ours is being tipped on its head. So we became quite private, I think, during that time. But yeah it was stressful. Oh it was more than stressful, it was absolutely horrendous. *David*

Fathers often reported becoming more "insular" and withdrawing from social circles as a result of their child's cancer and an increasing sense of separation from the normality of "everyone else's lives". While there was some choice exercised in the decision not to see other people, most fathers accepted the role of Lone Wolf as there was "nobody to talk to, to actually really talk to". This lack of support from those around them and experience of isolation could be "stressful" and "horrendous" for fathers. While this was the reality for most fathers in this study, a few fathers reported experiencing offers of support from friends and family:

The support – absolutely incredible. We had food for months and months and months. Literally didn't have to cook which is such a cool gift. If you could put something in there that people need to know that not everyone needs to make lasagne though! Because it was so hectic at one stage I think I had banana cake for dinner a couple of times ... There's nothing that people wouldn't do but then it took us a lot to accept stuff as well. We wanted to cope ourselves or didn't think we were putting on a brave face 'cause we weren't but I think we thought we could deal with it ourselves ... we all want to pretend we're braver than what we are. I think we all want to be that protector, we want to be in charge and I'm fine, I'm okay. *Dan*

I wouldn't so much say charity but more of what people do to try and help you. It's phenomenal at times. You'll get people, "Anything we can do to help you, give us a shout," but you never want to ask. You never want to say, "Can you give us a lift?" or, "Can you do this?" Because you want to just do it yourself, you want to get on with it and get it done yourself. *Andrew*

While Dan received an “incredible” amount of practical support through the provision of meals, and Andrew received many offers of help, they still exhibited many characteristics of the role of Lone Wolf through their reluctance to accept the help of others, and belief that they should somehow “deal with it” themselves. Dan also explains that it is important for fathers to feel like they are “in charge”, and the “protector” of their family. There is a sense that Cancer Dads need to reassure themselves and the outside world that they are “braver” than they feel, and that they are “fine” and “okay” by not appearing needy or desperate for help from others: “you never want to ask”. These expectations that Cancer Dads would appear self-sufficient and conceal any vulnerability were also apparent in fathers’ relationships with their male friends:

Friends tried to help, they had a certain amount of empathy but being men, it’s not easy to help another one who’s in pain. As a male you feel isolated and when you try to show emotion you’re frowned on for doing so. Basically, I had my masculinity ripped out from under me by certain other people that I worked with for showing any emotion. I don’t know what else I was supposed to do. *James*

The dads – we go on days out and all the rest of it but even when we go on the days out, we don’t talk about it. You go there and you have a bit of a laugh but you don’t talk about, you don’t really say anything about what’s going on or what you’re going through or what’s happened or anything else like that. It’s like you’ve got to man up and get over it and get on with it and just do it. It’s not easy at times. *Andrew*

Fathers often struggled to share their feelings with other men, as they felt “frowned on” for showing emotions that might be perceived to be unmanly. James reported a particularly strong experience of having his “masculinity ripped out from under” him by unsympathetic male workmates while Andrew described a general expectation that he would “man up and get over it” and “get on with it and just do it” without acknowledging or talking about his emotions. However, fathers felt that following this “harden up” message would not meet their emotional and support needs and they expressed a quiet desperation at the lack of alternative options: “I don’t know what else I was supposed to do”; “It’s not easy at times”. Men’s friendships have been described in masculinity literature as part of a performance of masculinity because of the fundamental way in which being male conditions and influences friendship behaviour among men (Migliaccio, 2009). The performances of men are judged by the dominant ideology of masculinity (Coltrane, 1994), for example ideas that men should

be emotionally stoic and appear unhurt and in control of stressful situations (Collinson, 2005; Harris, 1995; Kaufman, 1992). As a result, men may be emotionally restrictive in their friendships as this is considered an appropriate masculine performance (Migliaccio, 2009). In this way, society's expectations of a man and understanding of masculinity may increase the likelihood that fathers will adopt the role of Lone Wolf by creating an unsafe environment for them to be emotionally expressive and limiting support they may receive from other men.

As Lone Wolves, fathers often turned to other parents of children with cancer, as the only ones who could understand what they were going through:

I guess the only saving grace for us, was that we were around other people going through it as well ... They had a lot of support from the other parents, being there for one another, and to be fair, for us, we were going through with our son, or what our son was going through in terms of his illness was nothing compared to what other kids were going through. *Mark*

I've learned a lot, and I've really opened up to sharing it with other parents, sharing the journey. *Ryan*

For Mark, support from other cancer parents was his "saving grace" in his role as Lone Wolf. Ryan also found great value in opening up and sharing with other cancer parents. There was also awareness among fathers that leaning on other cancer parents for support carried an expectation that they would in turn provide reciprocal support, "being there for one another". For some fathers, this was considered too risky and too difficult:

I just didn't want to process other people's emotions at the same time I was processing mine. I've really tried to isolate that, that's why at the beginning I didn't talk to anybody in the hospital, I didn't want to know. I did initially and then we spoke to someone and they've got this and their kid's relapsed and this has happened and you go, I don't want to be processing that as well as my own stuff. *Caleb*

I personally found it hard to talk to other parents who were going through this myself. I don't know whether that was shyness on my part or I don't really know what to say. The majority of the parents that you did meet and talk to were all good people, all normal. And you always felt guilty when you found out that they lost their child and you've still got yours. *James*

Some fathers felt the need to further retreat into their role as a Lone Wolf in order to protect themselves from the intensity of other cancer parents' emotions and the

reality of relapse and death for some families. The danger of becoming too close to other cancer families, who might lose their child to cancer, or experience a relapse, was too much for some fathers and informed their decision to isolate themselves from other families. At this point, fathers became firmly entrenched in their role as a Lone Wolf, as they felt unable to entrust their emotions to those outside or inside the cancer world. Out of necessity, fathers became reliant on developing sufficient inner strengths and private ways of managing the emotional turbulence of their child's cancer treatment. This sense of isolated suffering and descriptions of the self as "alone" and "strong" were also reported by fathers in a study by Nicholas et al. (2009).

While fathers felt unable to turn to others for emotional release, they emphasised the importance of finding other ways to express their feelings:

I suppose Dads want to know they're not alone. And all Dads, I'm not, but all Dads are these sorts of tough ass guys who don't want to cry, so need to find a way to let them open and vent their emotions as well. I can only speak for myself. I don't know how, but they need to get rid of those emotions, because if it builds up it becomes negative or aggressive. Or I wouldn't say it would lead to suicide, but it would lead to some really depressing times in my thoughts in that situation. But that needs to be controlled I think ... But they need it, I guarantee it. I've talked to a lot of fathers up there. *Robert*

Some of it's culture, it's attitude. The New Zealand culture is toughen up, harden up, get over it. That's got to be broken down because it's wrong and I think there's certainly areas there where if there isn't that area of venting the frustration, it can be taken out as violence and whatnot. That facility to be able to openly talk about it but the problem you've got with it is actually getting the male to open up and admit that there's a problem. I think you'd struggle on that on every single time. *Andrew*

These two fathers recognised the crucial nature of the need for Lone Wolves to "open up and vent their emotions" about their child's cancer. Andrew challenges the message of New Zealand culture that men must "toughen up, harden up, get over it" and suggests that this has had a detrimental influence on the ability of fathers to "open up and admit there's a problem". Both fathers are worried that in the absence of a "controlled way" to express the intensity of emotions associated with the cancer experience, fathers may end up struggling with "aggressive" tendencies or depression. For many fathers, this is the foremost challenge in their role as Lone Wolf - how do they

maintain their masculinity in the eyes of those around him while also safely processing their emotions? Do they need to step outside of the role of Lone Wolf and find a new way of expressing their emotions while preserving their masculinity? Fathers reported finding a number of different ways of expressing their emotions safely in isolation:

My wife's a big talker, that's her way of coping with things. Me, not so much. Some days I didn't want to talk about things ... I tried everything. I tried sleeping more, I tried eating more, a bit of binge drinking – tried that a few times. Stages of deep thinking, a few discussions with God, well, He did a lot of listening! A mixture of the lot. Yeah, had that [a punching bag]. I've got it in the garage. I drew a picture of a face and it was the cancer face. I used to beat it up. Sometimes you're so angry you don't know what to do. Why your kid? *Dan*

I just cried alone in the car ... I've never really needed to express my anger in a physical way. In saying that, like other guys, I might get angry and punch something or I might yell a bit more. But I didn't need a physical outlet as such. A virtual world was more than enough to meet those needs ... In some ways, I got better support from these people I've never met. *James*

I would just go to the gym and take it out like that. I play football, and just trying to get rid of the stress that way. Otherwise, didn't really have any other way to get rid of it. There was no one to yell at. But I was rushing about a lot, I'd race off and go to the gym and then come back. But I think in terms of stress release, I have a home gym, going mad for half an hour and feeling better afterwards. That let out a bit of steam. *Mark*

Most fathers were able to set aside the emotional restrictions they felt as a Lone Wolf in private by finding ways to vent their emotions about their child's cancer. For many fathers, a physical outlet was a significant way of releasing stress and pent-up emotions. Dan reported having a punching bag in his garage with a "cancer face" drawn on it. Beating up the "cancer face" was a safe way of releasing his anger and frustrations at the unfairness of his daughter's leukemia diagnosis. Dan also reported experimenting with lots of different strategies such as sleeping, eating, binge drinking, deep thinking, and praying in order to find an effective way to express his emotions when he did not want to talk. Mark also found a safe way to vent his emotions – in the sports field, and in his own home gym, where he could go "mad for half an hour" and feel better afterwards. However, not all fathers used physical outlets to vent. James

found support in the virtual worlds of online gaming through chatting to other gamers, and distracting himself from distressing thoughts about his daughter. When he needed to emote, James withdrew to his car and found a safe place to cry. It was important for fathers in the role of Lone Wolf to find private and safe methods of expressing their emotions. Fathers that struggled to do this, and ended up suppressing their feelings, found that the feelings resurfaced in other ways:

That was one of the few things that caught me up later on. Started getting angry. When it all finished, I got angry about the whole thing. It's like, I can't believe all this. I don't know what it was. Couldn't get it, I just flipped like that. It was stupid ... for the last five years you've put your emotions in a bag and you've left them there, now they're all starting to come to the surface. *Jack*

I just know the stress, the trauma, the loss that you go through. And it's hard, in some instances, actually to express it and to tell somebody about it ... This is really the first time I've really spoken about it and that's only because I've gone, this is probably worthwhile so that somebody understands what somebody goes through in this kind of situation and they can then help others go through it. As I say, certainly all that I did was hide it. There are times when you are on your own, you've got nothing else to think about and you vegetate over it and it's not healthy. It's really not healthy. You'll have an argument and it'll be over something completely and utterly trivial but you have to have that just to get your frustrations out.

*Andrew*

After pushing aside his emotions for several years during his son's leukemia treatment, Jack found that his anger "caught ... up later on". He was unable to find a safe way to emote during cancer treatment, and decided to see a counsellor post-treatment to process those emotions. Andrew also hid his emotions, and found that he was having arguments with his wife "just to get your frustrations out". While Andrew recognised that ruminating about his son's cancer was "really not healthy", he was unable to "actually express it and tell somebody about it". As a result, the research interview was the "first time" he had talked about the "stress, the trauma, the loss that you go through". Like many other fathers, he communicated strongly that one of the most challenging aspects of being a Cancer Dad was the sense of isolation and lack of support as a Lone Wolf. His reason for participating was to in some way assist in providing a greater understanding for others about the Cancer Dad experience so that "they can then help others go through it". Many of the other fathers echoed this reason



for participation in the study and emphasised that one of the key areas that needed to be addressed and better understood was the importance of support and finding a safe way to vent emotions.

## **Summary**

This chapter explored the ways in which Cancer Dads sought the inner strength to support themselves and their families through the trials of cancer treatment. In the role of Emotional Rock, fathers felt pressured to put on a mask and hide the intensity of their own emotions so that they could provide emotional stability and support for their families. In the role of Lone Wolf, many fathers felt isolated and disconnected from social support and struggled to express their emotions in front of others, perceiving that they would be judged negatively and seen as less masculine if they did so. While some fathers found support through other parents of children with cancer, the majority of fathers found a way in which to vent their emotions in private. Overall, fathers learned the importance of finding a safe way to acknowledge and express their emotions about their child's cancer.

## Chapter Five

### Cancer Dad and Juggling Responsibilities

Due to the intensive and demanding nature of treatment, many parents had to adjust the ways in which they shared breadwinning and caregiving duties, and a major challenge for many fathers was finding effective ways to balancing their work and family commitments during this time. This chapter explores the secondary roles of Breadwinner and Caregiver which Cancer Dads juggle throughout their child's cancer treatment.

#### Juggling Responsibilities

##### Breadwinner

Historically, effective fathering has been associated with the role of the provider and the ability to provide economic stability for one's family (Neil-Urban & Jones, 2002a). For many fathers, the role of Breadwinner was a normal and accepted part of fatherhood; at the time of diagnosis, all but one Cancer Dad was engaged in full-time work. However, following their child's diagnosis, both parents faced the challenge of redistributing home and work responsibilities in order to meet the increased caregiving demands associated with intensive treatment and hospital stays. For many fathers, this meant remaining in full- or part-time employment in order to meet the ongoing financial needs of the family, as well as taking on additional childcare or household responsibilities. While there were a diverse range of challenges associated with adapting the role of Breadwinner, many fathers saw their work and financial provision for their family as a fundamental part of their role as a Cancer Dad:

As a father, you're the caveman – be there to support your family. I've always been the main breadwinner for the family, I fix stuff around the house, the kids tackle you and you're the caveman of the house. *Caleb*

So as a father you've got to provide better. I think, in my case, that's the way I cope. So I make sure we've got really good food in the house, we've got money ... It's been my goal to make sure everything's in the house, filled, built, stuff like that. I do all the cooking... So that's the focus, and how I'm coping. And my role is to provide the best environment for them. Yeah, as the father, that's the best – to give them the best that we can. Because

we don't know how long he's going to be around. So if he survives, all good and well, but there are kids there who are in relapse now. *Ryan*

Caleb establishes that as the “caveman” of the house, one of his key responsibilities is to be the main breadwinner for his family. Ryan also identifies with this responsibility to provide for his family, and emphasises that he feels driven to “provide better” for his children now that his son has cancer and they “don't know how long he's going to be around”. This suggests that a realisation of the uncertainty of their child's future can for some fathers intensify this desire to provide and “to give them the best” they can. This increased responsibility to provide for their family's needs was reported as stressful for a number of fathers, particularly as their wives often left their jobs in order to meet caregiving demands for the sick child:

My wife was working; she had to stop work that day basically so you've got one salary walking out the door. It doesn't make life easy financially. *Caleb*

Trying to keep that all together at the time was hard. Because I was the main earner, that's where the financial ... it got pretty hard. We always had enough to give people what they needed, there's never enough to give them what they wanted. It was pretty mind-numbing. *James*

The loss of one income was a significant financial stressor for many cancer families. This was challenging for fathers in the role of Breadwinner, as they had full responsibility to meet the family's financial needs and often were unable to provide at the same level that had previously been able to, prior to diagnosis: “we always had enough to give people what they needed, there's never enough to give them what they wanted”. Fathers were also aware of other Cancer Dads who had struggled so much with loss of income that they were unable to meet mortgage payments and had to sell their family home:

I suppose I'm lucky because I've got a good job ... But there's some people out there, it's horrific, absolutely horrific. On top of what they have to go through, to sell your house. Ouch. We were very lucky ... You know they're going through a hard time as it is. The last thing people want to find out is about your easy time in a hard time, you know, they have a hard time in a hard time. *Jack*

Jack was distressed by the plight of fathers who were forced to sell their family home because of financial difficulties stemming from their child's cancer diagnosis. To experience that amount of financial stress, on top of the emotional and practical stresses related to having a child undergoing treatment for cancer, seemed like a

“horrific” burden for a father and a Breadwinner to carry. The decline of family finances would also provide a strong challenge to fathers’ sense of competence and adequacy, as despite increasing numbers of women in the workforce, the traditional view of the father as the Breadwinner and provider is still valued strongly in society (Dienhart, 1998; Simon, 1992).

In addition to the stress of being the main Breadwinner, a number of fathers also emphasised the difficulty of concentrating while at work:

We know there are other parents out there that are struggling ‘cause, man, is it scary! Especially if the main breadwinner can’t do their job properly either. Because I’m sure the fathers would want, and I’m speaking for myself here, I know I personally would’ve wanted to be more at the hospital than at work and I don’t know how they could concentrate on their job when they know they’ve got a child in hospital going through that. *Max*

It was interesting, I’d just started a new role, Laura got sick and then my Mum died. So, three big things happening at once. Work was bottom of the list there and probably until about two months ago, I haven’t been that involved at work, I just couldn’t focus for the day. I haven’t really delivered a hell of a lot this year and I can’t see how people could or would ‘because you’re distracted all the time. *Caleb*

While fathers saw their role as Breadwinner as an important responsibility, they often struggled to push aside worries and concerns about their sick child and to stay engaged in their work. A conflict between work and family obligations has also been reported as one of the primary challenges faced by fathers during their child’s cancer treatment in a study by Brown and Barbarin (1996). While work was considered “bottom of the list” in comparison to the needs of their sick child, fathers were aware of the necessity of their job for family finances and that their employment could be at risk if they were not able to deliver what was expected. This was a “scary” and stressful prospect for fathers in the role of Breadwinner. Trying to attend to the financial as well as practical needs of their family resulted in stress and exhaustion for many fathers (Nicholas et al., 2009):

Could lose my son. If I lose my son, my wife may end up topping herself. I’ve got to earn money so I’ve got to go and do my job. I can’t afford to get stressed out at work ‘because I get stressed out at work I’m going to lose it all and I’m not going to be able to do that. I’ve then got to support the family, not just financially but in all the other ways as well. I’ve got to make sure

that the kids go to school, the kids are protected from what's actually going on with Alex." *Andrew*

It was the pressure that they kept putting on me and they just kept on my back and pushing and pushing and pushing and wanting and demanding... trying to make myself more efficient and trying to deal with Jessica's illness, it just takes its toll. You're like, "What more can I give you when I'm already giving you all I got and you're not allowing me enough of myself to give to my family?" *James*

James and Andrew both struggled with the stress associated with meeting employer expectations and trying to keep their job. Andrew emphasises the desperate importance of his role as Breadwinner – although he is stressed out by the possibility that he could lose his son from cancer and his wife from suicide, he must contain his stress at work or he might “lose it all”. In addition to the stress of working in an environment where he cannot afford to fail or “get stressed out”, Andrew must also maintain his composure at home in order to protect his children and practically support them. James also struggled with the “toll” of a continually stressful job that he could not afford to lose and suggested that attempting to meet these demands did not allow him to retain “enough” of himself to give to his family. Chesler and Parry (2001) have similarly argued that social pressure and the threat of job loss can often become hindrances to fathers’ ability to devote energy or attention to their children, as well as to their capacity to personally cope with their child’s illness, and to support their wives. Furthermore, a strong relationship has been reported between the financial burden experienced by parents and their personal coping and social isolation (Mailick, Holden, & Walther, 1994). In this way, work demands can contribute towards fathers’ feelings of alienation and isolation from their child’s care:

As a dad, you feel that you're useless. There's nothing you can add, there's nothing you can do. Certainly while you're going through it, you might be doing loads of stuff but you think there's nothing you're really doing because you're not helping in the immediate sense. *Andrew*

While Andrew was contributing significantly through finances, housework, and care of the other children, it was easy for him to push these achievements aside and feel “useless” because he was unable to be directly involved in his son’s hospital care while in his role as the primary Breadwinner. However, not all fathers faced these challenges in their role as Breadwinner, or experienced a sense of alienation from their

child's care, as some fathers reported receiving generous and understanding responses from their employers:

It's quite fortunate that my son plays soccer with one of kids of the general manager of the business so I was able to basically pick up the phone straight to him and say, "Look, this has happened, I just need to be out of work for a while", and he said, "Take as long as you want. It's no issue at all". I didn't ask them for sick leave; it was just, "Whatever you need to do". I would've had three months off and it's all been fully paid, no issue. *Caleb*

The boss basically said, "You don't need to come in". We have a sick leave system which includes family sick leave so it's unlimited essentially. *Dan*

And I was lucky ... they gave me a month off work, just like that. And then they let me work for two months out of the hospital effectively. So starting leaving the hospital at 9, and knocking off and going back at 4. So from that point of view, yeah, it was a bit stressful, it was just unbelievable at times. It was really hard. My employer was so good about it, that they did relieve a lot of that stress that was related to work, and they were very understanding. They were pretty lenient on my hours. So I was very lucky. But I was in a position in my job that allowed me to do that, flexible job, so I always remember that was the one thing they did that, that really helped.

*Mark*

Several fathers reported their relief and gratefulness at their employers for allowing them time off or flexibility so they could help care for their sick child. Fathers described themselves as "lucky" and were fortunate enough to have a lot of the stress associated with their role as Breadwinner relieved for some length of time. For Breadwinners with generous or flexible employers, the chance to spend more time attending to the needs of their sick child was seen as invaluable. One father was particularly fortunate to be working for a large international company who promptly gave a substantial donation to the oncology ward at the hospital and promised the father full pay regardless of any time he needed to take off:

My company, I was on full pay every day, they gave money to the hospital ... I think day 3 or 4 they gave \$30-40,000 Australian dollars to the ward directly ... My mind is always ticking for work, I can't switch it off. I think it's definitely the work focus was an outlet ... if you're sitting beside her and she's sleeping and you're doing work, you're still there but you're venting.

*Robert*

Robert felt very supported and uplifted by his company's goodwill donation and invitation to take time off as needed. This took the weight of the burden of financial provision off his shoulders, and while he still chose to work at the hospital while his daughter was sleeping, he was not under pressure from his company and was able to use his work as a distraction and outlet. Many of the fathers who were given paid time off or flexible working hours were from larger companies, where doing this for one employee did not have a big impact on the company as a whole. However, the situation was more complicated for two fathers who owned and managed their own businesses:

Cause we've both got our own businesses, and we've seen massive downturns in our business. I see a lot of people who just leave their jobs and go on the sickness benefit. But we couldn't afford that. We'd lose our business and the investment we've put in, would go down in the shizzler completely. So it's a hard decision on the whole family. *Ryan*

[Work] became very secondary ... I own my own business ... Because we're a small business, a lot of the work that's done is me, and so ... there is obviously the danger that some things would not get done or get overlooked and would have a knock-on effect further down. But I contacted a lot of our key people in the business ... explained the circumstances, and said you guys need to help me out. And everyone was amazing. I still had to be absolutely hands on, so that was another thing I'd have to do at night time when ... everyone was in bed. The business suffered a little bit, but not a hell of a lot. So your traditional working hours fall out the window, but it's amazing what you can get done in chunks of time when time permitted. *David*

For these two fathers, the conflict between home and work commitments was particularly difficult. It was a "hard decision on the whole family" as they had invested and built up their own business and "couldn't afford" to lose the investments they had made, but at the same time work became "very secondary" to the needs of their sick child. While Ryan and David were well-used to their role as Breadwinner, and the commitments that entailed, changes in their family circumstances now meant that juggling ongoing work obligations with needs of their sick children was very challenging. Ryan was in the particularly difficult position where his wife also owned her own business, and their businesses both suffered "massive downturns" as a result of the time as a result of time spent away from work. David similarly had to stay "absolutely hands on" and squeeze in working hours at the hospital and late at night after everyone was asleep. It is clear that in trying to balance their role as Breadwinner



and family commitments, many fathers were forced to make sacrifices in the areas of income, time spent with their children, sleep, and free time.

While fathers with their own businesses faced significant challenges to their role as Breadwinner, some fathers faced even greater challenges as they experienced job loss or disciplinary actions, as a result of their family commitments:

And even my work, they gave me special leave, but not for the three months. What happened was, they gave me special leave for a month, then I went back to work on and off sort of thing, took some sickies and then got made redundant. Which in a way, it was a blessing, so I could stay home and look after my son, and my wife could work. Her job was great, flexible. But we managed. We had good family support. *Luke*

Between then and the first two years, work/life was made very unpleasant for me based on the fact they had no empathy. My second day back at work after I'd told them her diagnosis, I was five minutes late and a big scene was made about it by my employers ... All they cared about was me being five minutes late whereas I just said to them, "I'm concerned about my daughter possibly dying and all you guys are caring about right here is five minutes." Every time I needed to go through to the hospital, you could just tell that they didn't like it. Then the discipline meetings started – they claimed that my work was substandard ... At no point was I ever offered a friendly shoulder to cry on, a chance to vent my frustrations. I'd come home and be so angry but then the other children needed me because my wife and Jessica were mostly at Starship a lot of the time so I had to come home and hold it together myself. *James*

Luke was made redundant by his employer, assumedly as a result of only being able to work "on and off" because of his son's cancer treatment. While Luke chooses to frame this positively as a "blessing" in hindsight, it seems as though this situation had the potential to be very stressful and was manageable for his family only because of the flexibility given to his wife in her job, and because of "good family support". Because of his wife's continued employment, Luke did not carry the burden of Breadwinner alone, and thus was able to focus on the positive outcome of more time with his son. However, James did carry the responsibility of being the sole Breadwinner in his family and reported suffering at the hands of employers who had "no empathy" during the first two years of his daughter Jessica's leukemia treatment. The use of disciplinary meetings to address any tardiness or "substandard" work was extremely

stressful and “unpleasant” for James, who then had to “hold it together” and suppress his anger at home so he could care for the other children. When fathers such as James had to manage increased household and caregiving duties, in addition to increased stress at work, the role of Breadwinner became a significant burden. James also struggled with a loss of income from the times he needed to be with his daughter in hospital and was told he was ineligible for a promotion:

They were never left in a pickle where their income was compromised. It was quite easy for mine to be compromised. It was not like I chose to take time, it's my daughter, my daughter's going through something that's pretty unpleasant so the more support she has, the better. To be ostracised for showing that level of support towards your family is a pretty hard thing to comprehend. Being told that I wouldn't advance up the ladder any further because of my family commitments was a pretty harsh kick in the stomach ... I left halfway through her treatment, I think, was roughly when I called quits.

James was angered by the apparent discrimination against him because of his commitment to support his daughter through her leukemia treatment. As a father and the sole Breadwinner for his family, it was stressful to have his income “compromised” and feel “ostracised” by his employers. James reported struggling with depression during this time, in part likely due to his stressful and unsupportive work environment. He was eventually able to address this by leaving and finding employment elsewhere:

When it eventually got too much ... I started to experience the depression. I was just the bigger target 'cause I was the more vocal in fighting back and at some point some people just make it their mission to break you. Unfortunately, I broke ... I didn't take any medication to get through it because it was an environmental thing, I was able to change that quite easy just by leaving the place.

Another father also expressed his concern that the threat of loss of income could be detrimental to a father's wellbeing in his role as Breadwinner:

In NZ, the male is the breadwinner predominantly still, and they feel quite threatened if they're going to come in this situation, they're going to lose their money, they're going to lose their wellbeing ... The last thing the father needs is in there, his world is falling down around him, and then all of a sudden, his income is gone, and you don't need to focus on things you can't control outside of the hospital. But that was a big one. *Robert*

Robert makes a clear connection between fathers' security in their role as a Breadwinner, and their wellbeing. In a time of vulnerability, where a father's "world is falling down around him" because of what is happening to his child, the additional threat of loss of income can have detrimental effects on the father's emotional and mental health, as illustrated by James' experience of depression. For some fathers, holding tight to the role of Breadwinner and seeing financial provision as a core identity may lead to negative consequences if fathers are made redundant, or unable to provide financially during their child's cancer treatment. As a male, the role of Breadwinner is often seen as central to their identity as a father (Basow, 1992; Bernard, 1981), and a perceived failure in this area can compound a father's sense of helplessness and uselessness, especially if this is an area of fatherhood in which they have historically felt competent and successful. Robert goes on to express his concerns about the treatment of Cancer Dads by employers in New Zealand and the negative impact this can have:

The other thing I saw was really bad from the Dad's side is employers in NZ are really mean. A lot of them lost their jobs, because they couldn't be at their job ... The worst case they should do is hold a position open for the father, they can pay out his holidays etc. One of them, the company was up there on a Wednesday night at Ronald McDonald house giving food and gave some money, what a load of crap, the day after they fired him, because you know, he's going to be there for another three, four months on and off ... And it doesn't hurt to hold their position open and get a temp in, but to disconnect them and cut them off and say good luck ... Everything is negative all of a sudden.

Robert was particularly concerned about the treatment of fathers of children with cancer who "lost their jobs, because they couldn't be at their jobs". For Breadwinners who were disconnected and cut off by their employers because of their need to support their sick child, this was often a negative and overwhelming experience, in the midst of an already uncertain time. Robert makes a case that companies should at the very least "hold a position open" for the father, and expresses his anger at a company who put on a façade of support one day and then fired a father the very next day. This issue of the need for greater advocacy for fathers in a Breadwinner role was also addressed by other fathers:

I know now that I'm a lot more sympathetic as an employer to parents in my organisation that have sick kids and it's probably not until you've been in that position that you really do understand what they're going through and I

imagine that some employers are absolutely ruthless and sometimes it might be really great if there's an independent, unrelated third party gets in the middle of it and says, "Hey, guys, David's stuck in the hospital with a very sick daughter. He's really concerned about work and the implications of not being at work. We're just going to get in the middle of this to see whether or not we can kind of broker some sort of reassurance or understanding or extended period of leave so that that stress that sits on David's shoulders is partially or totally taken away." *David*

I think in some cases, fathers who went through what I did with work, I think employers need to be actually sat down ... Yeah, and have it all outlined and explained that your worker isn't finding a crutch to allow himself bad behaviour and bad workmanship, but his mind's not on the job sometimes. *James*

David and James argue for the importance of finding a third party to bring about "reassurance" and "understanding" for both the employer and the father following a child's diagnosis with cancer. Given that financial stresses can increase the burden of and pose a serious threat to the wellbeing of Breadwinners, fathers with employers who may not fully understand the nature of childhood cancer, and the extent of its treatment, may benefit significantly from advocacy in this area.

## **Caregiver**

According to social role theory (Eagly, Beall, & Sternberg, 2004), fathers have been guided by traditional ideals of masculinity to view caregiving as secondary to their primary role as Breadwinner or provider, and as primarily the domain of women. However, researchers (LaRossa, 1988; Ranson, 2001) have noted that an increase in the number of women who work since the 1980s has, in part, driven a subsequent cultural shift in expectations around fathering. As portrayed by film and media, fathers are now expected to be more emotionally involved, nurturing, and committed to spending time with their children (Wall & Arnold, 2007), and the idea of fathers as co-parents is beginning to emerge (Craig, 2006). Yet researchers (e.g. LaRossa, 1988) have also highlighted a discrepancy between new ideals about fatherhood and practice, as studies (Craig, 2006; Fox, 2001; Singley & Hynes, 2005) have indicated that in dual-income families, mothers still bear the majority of the responsibility of childcare and spend considerably more time with their children than fathers, particularly while the children are younger (Silver, 2000). Researchers (Wall & Arnold, 2007) have

challenged the extent to which the culture of fatherhood itself has changed as there continue to be persistent social expectations that fathers will continue to be responsible for the majority of breadwinning duties, and mothers will be responsible for the majority of caregiving duties (Fox, 2001).

Contrary to the traditional division of responsibilities, a number of fathers found themselves in the role of Caregiver following their child's diagnosis with cancer. This role of Caregiver varied across fathers, some of whom became responsible for the primary caregiving of their child, while others played a 'tag-team' role and shared care of the sick child with their wife, and the remainder took responsibility for secondary caregiving duties such as looking after their healthy children. This Caregiver role was a challenge to societal norms of fatherhood and masculinity, particularly for fathers who engaged in the role of primary Caregiver:

What I did was I straight away resigned. I basically decided I was going to take on the caretaker role and my wife stayed at work. It was also a no-brainer 'cause she earned a lot more than I earned so even though she would like to have stayed behind and looked after, there was no question about it, she would do that and I would take care of her. *Owen*

Initially, there were some discussions around what we were going to do and who was going to do what. I think one of her problems was she wanted to be able to do more but couldn't because she had a 4/5 month old baby ... It was purely practical, because Mum had a baby to look after. She couldn't bring the baby to the hospital ... Someone had to be with Michael pretty much the whole time he was in the hospital, and that fell to me. I was the one who stayed at night about 90% of the time. *Mark*

Back then I stopped work and we survived. I looked after the kids and we just changed roles, really, and I have no problem with that. Cooking is not a foreign thing for me. And that's the way it's been, but I definitely didn't put my hand up for leukaemia. Getting back to the hospital side of it, 90% of it was me. Not taking anything away for my wife. She was there as much as she could be, but she also had a business to run, so the long haul I was there ... There was a big gap there where I was doing a lot of it, especially the side effects, the long side effects like the diabetes and the constipation and a few other things that happened. *Max*

For many fathers, their transition to the role of primary Caregiver was necessitated by practical reasons or circumstances. Owen's shift to the Caregiver role

from full-time work was a “no-brainer” on financial grounds – the family needed to retain his wife’s higher salary. Similarly, Mark’s role as primary Caregiver for his son Michael was a “purely practical” decision because his ex-wife was not able to bring her young baby into the hospital environment. For fathers who took on the primary Caregiver role for the first time, this represented a significant change and adjustment from their previous responsibilities – not only were they primarily responsible for the care of their healthy children, but also the care of a child with cancer. This was a daunting prospect even for Max, a father who had taken on the role of primary Caregiver a few years ago but “definitely didn’t put up my hand for leukemia”. However, while some fathers needed to adapt to the Caregiver role, each father expressed a desire to be involved in their child’s life and help out in any way they could, even though caregiving in the cancer environment was intensive and demanding. Fathers who continued to have work responsibilities as well as being a primary or tag-team Caregiver, had the additional difficulty of juggling work commitments, and often found this exhausting:

We have to toilet them, we have to watch their IVs, notify the nurses when IVs have run out, you know, you’re up every 45 minutes throughout the night. You get some massive sleep deprivation. And then my wife would come in, in the morning, and I’d go to work ... I was literally falling asleep in the car at traffic lights. So you’ve got to watch all that sort of stuff, cause you get absolutely wrecked doing it. *Ryan*

For some fathers, the roles of Breadwinner and Caregiver were directly in conflict. Ryan struggled to work following “massive sleep deprivation” from caring for his son in hospital, and felt like he was getting “absolutely wrecked” trying to engage in both roles. However, Ryan chose to continue being engaged in the care of his son, and to prioritise his role as Caregiver, in spite of any negative impact on the success of his business. Ryan’s struggle to juggle caregiving and work is consistent with past research suggesting that fathers experienced significant practical and interpersonal stresses when trying to balance competing obligations associated with work and home (Chesler & Parry, 2001), and that these stresses were amplified when the child was hospitalised (Cook, 1984). However, fathers with less work commitments and the help of their spouse in caregiving were able to achieve more balance:

We did every day that she was in hospital, we had a day about, did 24 hours about. My wife gave up work just ‘because it would’ve been impossible otherwise. We’d do day about at the hospital, 24 hours which we were really lucky ... Did I spend a lot of time in hospital? Yeah. Initially



we were there a lot. We get told and we understood that you're no good to her if you're not healthy yourself. By having that 24 hours away you'd get a half-decent sleep or maybe get up in the morning, seeing our son and sorting him out so you get to see him as well. Sort him out and then it's time to do some washing and cleaning up or going for walk or a run or to do something for yourself. *Dan*

Dan received helpful advice from the hospital about the importance of looking after himself and his health so that he could be of the utmost help to his daughter with leukemia. He was able to share primary and secondary caregiving responsibilities with his wife, allowing him to get a "half-decent sleep", spend time with his son, and perhaps do something for himself, on the days his wife was at the hospital. Dan recognises that he is "really lucky" to be in such a privileged position where he was relieved of work-related stresses and able to focus on his role as a Caregiver. Fathers that were able to secure paid leave were able to avoid the stress of juggling work and Caregiver responsibilities experienced by other fathers, and as a result seemed to be able to focus more energy and attention on their children, and reported feeling less stressed and overwhelmed.

Fathers who acted as a Caregiver went out of their way to care for their child as best as they could. For Dan, a pivotal task was managing his daughter's weight during the periods of time she was in hospital. Dan brought along a packet of cheese balls and a carton of eggs (see Figure 10) to his interview as a narrative tool to bring perspective to his role as a Caregiver of his daughter. Dan explained how he used these foods to coax his daughter into eating during times in hospital when she was struggling to maintain a healthy weight:

She was 37 kilos when she got diagnosed and she got down to 22. She didn't look too bad there. You can see she's pretty skinny. So, our daily struggle was food as she got pretty fussy. The hospital food – there was not a chance she was going to eat it hence the eggs. She went through a stage of eating eggs four, five times a day. One scrambled egg sort of thing and cheese balls. It didn't matter when or why, she just needed energy and high fat.

As a Caregiver, Dan's concern was that his daughter Charlotte did not lose too much weight during her treatment and he uses the packet of cheese balls and carton of eggs to represent his dedication to care for his daughter's complex needs.



Figure 10. A photograph showing a packet of cheese balls and a carton of eggs, the main foods eaten by Dan's daughter Charlotte during stays in hospital.

As a primary Caregiver, Max also looked out for the physical and emotional needs of his daughter and brought along his daughter Hillary's favourite toy (see Figure 11) as an representation of this. He described caring for his daughter Hillary by ensuring she had her favourite toy with her during painful medical procedures:

“She's got her bear. She loves polar bears, and she got given that when she was obviously an infant and that still goes with her regardless. When she has the lumbar punctures, she still takes that with her and she wakes up with it still there ... It's been a comfort thing. That's the one that goes with her all the time.”

In the role of Caregiver, fathers such as Max cared for their child's emotional wellbeing, alongside their physical and medical needs. Bringing along his daughter's well-worn and favourite toy enabled Max to add depth to his narrative and convey to the audience the way that he recognised and catered for his daughter's need for comfort and security in the midst of treatment.



*Figure 11.* A photograph showing Max's daughter Hillary's favourite toy, a polar bear which comforted her during medical procedures.

Robert was also able to recognise the importance of keeping up his daughter's spirits in his role as Caregiver:

Most energy from me was definitely going into keeping the family positive, and keeping Emma even more positive.

However, assuming caregiving responsibilities at the hospital was not without its share of challenges for fathers, who were aware that they were in the minority:

There are probably more females up there looking after their children than males, definitely. The males up there probably didn't have all the

information they needed, or the support ... I suppose you become offensive, or defensive when you're in that situation. *Robert*

Well, the normal role of the father is he goes to work and comes home, and in the old society caregiving is left up to the wife. Because that's usually how it goes ... I'm not a normal role ... I just deal with it. *Max*

Fathers acting as Caregivers in the hospital environment were aware that they were challenging societal norms and the "normal role" of the father and at times felt undervalued because of this. While Max claimed that he just "deals" with his counter-cultural role as primary Caregiver, Robert argues that fathers in the hospital probably felt like they were not offered adequate information or support and might get "offensive or defensive" as a result. While most fathers reported fair and supportive treatment from hospital staff, several fathers felt unappreciated in their role as a male Caregiver:

But one thing I have to say, being a male and in the hospital, it is very geared for the mothers. I could be there, for example, just that Sunday we went there, my wife had gone out to go downstairs and the doctor had come in, one we hadn't seen before, and was talking to me fine, as like this. Then the minute my wife came in, I might as well have fallen out the window. Constantly looked at my wife. I was not there anymore. To me that hurt me, it annoys me. *Max*

They'd be explaining more to her Mum, really, than to me because they saw her Mum spent more time with her. A lot it's the social mindset that fathers are just doing it because, well, they've got no choice in it ... At times you're made to feel second-rate ... When you think about it, the way things are structured, we're still running on a structure from the 1930s and '40s, really, in the way things are being thought about with men and women. I still think we're still suffering some of the closed-mindedness from the past and it's still being brought forward to now, to the present where it doesn't belong. *James*

Max and James struggled with being treated as "second-rate" by some staff at the hospital. Max felt hurt and annoyed by the doctor's immediate transfer of attention and conversation to his wife when she walked into the room and asserts that he felt ignored to the extent that he "might as well have fallen out the window". James also felt like he was suffering from "closed-mindedness from the past" which had led to the assumption that he was only acting in the role of Caregiver because he had no choice in the matter, when in reality he was fighting his employers to spend more time with his daughter.

Max goes on to share another example of a situation in which he felt undervalued by a medical professional in his role as primary Caregiver:

At times I got quite angry with it, especially with the lady from diabetes, when she was first diagnosed with having this diabetes ... the doctor came up from downstairs and all the talking was to my wife and we had already said, "I'm going to be there. I'm going to be the one, talk to me," but she kept on talking, so I had to physically get up... I had to get up and come over to her and I said, "Now, look, talk to me 'cause I'm the one that's going to be doing this tomorrow. I need to know. My wife's not even going to be there." And she got so flustered, it threw her off the track ... But I shouldn't have had to have done that - make a point. Maybe it's just me, I dunno. But it is noticed by a lot of the dads and it's something that's there. *Max*

In this situation, Max felt compelled to fight against assumptions based on traditional role divisions and to confront a specialist in order to get clear instructions about how he, as the primary Caregiver, could manage day-to-day care of his daughter's diabetes. He also felt angry that it was necessary to "make a point" and stand up for his role as a Caregiver in the hospital environment. The difficulty for fathers of stepping into a role which has traditionally been mother-dominated has long been recognised: May (1996) identified fathers as the forgotten caregiver. Similarly, Chesler and Parry (2001) argue that the social structure of the hospital can reinforce gender-based role patterns. As mothers are usually the primary caregivers of their children, they often assume the major nursing role and are involved in relaying information to their husbands and other family members (Chesler & Parry, 2001). In addition to this, female doctors are heavily represented within the paediatric field in comparison to other areas of medicine (Groves, 2008). These two factors may contribute to a paediatric oncology environment in which some staff may be better accustomed and more comfortable relating to mothers, and may perceive fathers as intrusive and less-competent caregivers of children with cancer (Chesler & Parry, 2001). In this way, fathers may report that they are ignored or assigned peripheral roles by medical staff, have less contact with health professionals, and receive less support from them (McKeever, 1981). This may in turn affect fathers' behaviours and relational interactions within the role of Caregiver, as they may become "defensive" or assertive in response to feeling undervalued and "second-rate".

Fathers expressed their desire for more inclusion and recognition in their role as Caregiver:



It'd be nice if the fathers are included a bit more, because we're doing the same hard yards ... Be spoken to. Include them when you're there as a family or as a couple. I know there's situations where it doesn't work, but in those situations where it does, include them. That's all I can say to that. Just include him. Make him feel included. Make him feel that he has a role. *Max*

Any opportunity they can get to actually help, they'll take but it's not recognised as much as it should be. All fathers want to more involved more than what they are but the actual demands of work and other aspects of the family life make it harder. Like I said, with the other children it was a logistical nightmare for me. I took on a lot of other things, some things I probably did well at, some things I probably failed at, some things I'm middling at, to allow my wife more time to think and be with Jessica. *James*

Max asserts that it is important to make a father “feel included” and “that he has a role” that is valued in the hospital setting. James similarly petitions for greater recognition of fathers who choose to become more involved with the role of Caregiver and take on additional responsibilities during their child's cancer treatment. Given that fathers of children with cancer face a number of challenges to their role as a Caregiver, and may feel undervalued in the hospital environment, it seems important that a greater awareness of the importance of fathers' involvement in their child's care is facilitated in order that alternative constructions of the father as a Caregiver may be increasingly accepted by society.

## **Summary**

This chapter explored the ways in which Cancer Dads juggled the responsibilities of breadwinning and caregiving. The demands of cancer treatment resulted in a variety of arrangements for fathers: some remained in the primary Breadwinner role, others divided breadwinning and caregiving responsibilities with their wives, and several became the primary Caregiver of their sick child and did not engage in any paid employment. Fathers who were Breadwinners felt the burden of responsibility to provide well for their families in this time of crisis and were challenged to varying degrees by stressful situations in which they had to manage conflicting work and family obligations. As a Caregiver, fathers challenged traditional societal norms relating to role allocation in order to become more involved in the care of their sick child and other children, and at times felt misunderstood or undervalued in this role. However, despite the practical and emotional challenges of caregiving, fathers valued the opportunity to be more involved in their sick child's care.



## Chapter Six

### Cancer Dad and Managing Relationships

This chapter explores the ways in which the role of Cancer Dad manifests through the relational roles of Father, Husband, and Family Man. Although these are all roles held by fathers prior to treatment, the cancer environment provides additional challenges in the area of managing these relationships. Fathers faced the challenge of changing relationships with their sick and healthy children, Husbands needed to negotiate the stress and strain that cancer treatment created in their marriage, and Family Men discovered the importance of spending time with their family.

#### Managing Relationships

##### Father

While Cancer Dads were well-acquainted with fatherhood prior to their child's cancer diagnosis, many found themselves re-evaluating their relational role as a Father as a result of their child's cancer diagnosis. The demands of cancer treatment frequently involved a change in relationship as Fathers often focused their time and attention on their sick child:

I spent so much time with her. I think a lot of dads have trouble relating to their daughters and I've just spent the best part of two-and-a-quarter years, half of that with her 24/7 and just talking random stuff. Sometimes talking about nothing, sometimes talking about lots of things. We've a pretty good relationship ... very, very lucky in that way. It's probably the big positive that I talk about coming out of the whole thing is the relationship with Charlotte.

*Dan*

Yeah, I know her a lot more, she mostly knows me a lot more. She's seen bad sides of me and I've seen bad sides of her, but that's just the stress we've gone through. I think it will come back more when she's older. When she's an adult she'll reflect on it a lot more. She's still very much, I know she's 13, but still very much a kid. *Max*

Dan and Max felt that their father-daughter relationships had grown stronger as a result of spending more time with their daughters during cancer treatment. While fathers have been found to generally be less accessible and spend less time with their children

on average compared to mothers (Lewis & Lamb, 2003), the demands of cancer treatment provided an opportunity for some fathers to be more available to spend time with their sick child. Dan viewed himself as “lucky” to be able to relate to his daughter on a deeper level as a Father, as a result of increased time together, and saw this as the “big positive” to come out of their shared cancer experience. Similarly, Max saw the diagnosis of cancer as a catalyst for growth in his relationship with his daughter – not only did he get to know his daughter better, but she also learned more about him as they experienced the difficulties of cancer treatment side-by-side. This experience of knowing their child on a much deeper level as a result of the cancer experience has also been reported in a study by Nicholas et al. (2009), where fathers of children with cancer described feeling grateful for the positive shifts in their relationship with their child that may not have taken place without the cancer diagnosis.

Several fathers in this study also reported that they were proud of the strength with which their child handled treatment:

I was quite proud of the way she handled her treatments. Her pegylated asparaginase injections consisted of a needle in each leg as close to the bone as they could get. She didn't even flinch for that and was quite proud of her for that. *James*

I think I got some real strength from Laura how she's dealt with it. She's really managed to process her emotions really well. She's been really strong throughout all of this and that's really helped me, I think, how she's dealt with it. *Caleb*

Actually, the nurses were blown away with her the first time she had the asparaginase, because most of the kids see these needles and, I kid you not, they're about that long, because as I said, they go right in, and they really sort of hold the kids down, 'cause a lot of the kids are young. She's actually quite an old child to be in there, believe it or not, even when she started off at 11. So, these needles came out and she was just sitting on the bed and the nurses came either side and put the spray on, a special cold spray that numbs, and just goes boom, and very stoic our daughter. She just sat there and just went, “You're going too slow and you're doing it right.” because the one nurse that was going slow she could feel it, but the one that went fast, was good. And they just were blown away. They said, “Can we take a photo of this? We've never had a child do that yet!” *Max*

In the midst of the difficulties of treatment, Fathers were able to experience a side of their child that they had never seen before. For many Fathers, seeing their child's strength and resilience in the face of painful and difficult treatments filled them with pride and also helped them to find their own strength. James and Max were "quite proud" that their daughters "didn't even flinch" and remained "stoic" when receiving their intramuscular injections. Caleb was also inspired by his daughter's strength and the way in which she "managed to process her emotions really well". Similarly, David brought along his daughter's radiation mask (see Figure 12) and used it to convey his pride in the "gutsy" way his daughter coped during her radiation treatment:

She was the first child that I think most, if not all, of the whole radiotherapy team had seen do without general anaesthetic every morning. It freaks adults out doing it. Coped remarkably well. It's pretty full on when you consider that you're lying on a table absolutely strapped, you can't move in that whatsoever. And no one can be in the room with her. She would've been in the room by herself for 10 minutes. Sort of a mark of how gutsy she is, really ... That mask holds a relatively significant piece in our memories anyway, and probably Rachel's ... She was going through hell and back,



*Figure 12.* A photograph showing the mask that David's daughter Rachel wore during radiation treatment.

and that she just kept going, gives you so much strength to go, right oh, she's the one doing it tough, not us. Let's support her.

Holding his daughter's radiation mask allowed David to reflect upon how he was able to draw strength from the visual reminder of the "hell" that his daughter had gone through and how she "just kept going" and did "remarkably well". Through the radiation mask, David adds another dimension to his narrative and invites the interviewer and audience to also reflect upon the reality of his daughter's experiences during treatment.

Another father, Jack, brought along a green beret (see Figure 13) and used it as a narrative device to represent his son's courage during cancer treatment:

It's my old regimental beret. I was in the Marines as a young lad, so I earned that. When he was getting better, he was still quite sick, he was neutropenic and we thought well, let's give him a challenge. A mate got a couple of those and sent them over. That's the cap badge on there, globe and laurel. So we arranged some tests, we had to run up the driveway, and we had to put the cuddly toy on the back and run to the top of the driveway. We had to do some commando tests and that. But again, it was more like what it stands for, it was about courage, it was about adversity, it was about cheerfulness, all of that commando spirit. So after we did all that, I presented a pair to the pair of them – Matthew and his sister. Again, it's a symbol of his courage, for me it was.



*Figure 13.* A photograph showing the regimental beret that Jack gave to his son Matthew in recognition of the courage he displayed during his cancer treatment.

Through the use of a common symbol of sacrifice and courage with the interviewer and audience, Jack attempts to communicate the significance of what he perceives his son Matthew has done, in overcoming many challenges throughout his treatment. He also petitions the audience to recognise the courage and cheerfulness of his daughter, in her role within the family unit, by including her in the “tests” and presentation of the beret. The green beret is an emotionally provocative object for many people, and Jack utilises this as a powerful way of drawing the interviewer and audience deeper into the narrative and his own emotional response to his children’s display of courage.

However, not all Fathers reported positive changes in their relationship with their sick child:

Initially it brought us really close together. Up until the last six months. But in the last six months, some of his feelings have changed towards what happened. He’s told me he felt that I let him down and there was one instance when I had to leave the hospital, so he had to be on his own one time. And he’s sort of focused on that a little bit now, I don’t know. So in the last six months, our relationship has broken down a little bit to be fair, but I still put it down to teenage things. He’s 15 now. So no, it brought us very close together originally. ‘Cause we actually hadn’t spent that much time together, because you know, he doesn’t live with me ... I guess spending that much time together did bring us very close together. *Mark*

Me and Alex, we used to play on the play station a lot together. We used to do a whole lot of stuff together; we don’t do that so much nowadays. That seemed to go by the by. He’s very conscious of other children at times and his temper’s very hot. Something’ll happen and he’ll break out – when I say his “temper”, he’ll blast out with something and then he might burst into tears ... We do shout at them or bark, whichever way you want to do it, when it needs to be done. But they don’t pay any attention to my wife when she says something to them. As soon as I open my mouth up, especially Alex, he’ll burst into tears. Neither of us knows why. *Andrew*

Some Fathers reported experiencing a rift in their relationship with their sick child post-treatment. Mark explained that while his relationship with his son initially deepened, it had recently broken down. Mark attributes this partially to his son’s adolescence, and change of perspective about the level of support he provided at the hospital. As puberty tends to result in a natural distancing between parents and

adolescents (Steinburg, 1987), this may well be a contributing factor, although the son's view of his father as a role model may also be adversely affected by his perception of his fathers' lack of support during cancer treatment. Andrew also reports that his relationship with his son has been affected post-treatment and that they do not play together as much anymore. However, he is unsure of the reasons behind the changes in their relationship and emotional interactions, as his son Alex will "burst into tears" if he tells him off, and has a hot temper. Both fathers are aware that a shift has occurred in their relationship but seem to feel helpless in repairing their relationship with their son. It is interesting to note that of the fathers in this study, those with a sick daughter were more likely to report a positive shift in their relationship, while those with a sick son were more likely to report a negative shift in their relationship post-treatment. This may reflect a difference between Father-son and Father-daughter relationships, in the context of cancer. A review of the literature (Russell & Saebel, 1997) has argued that father-son and father-daughter relationships are distinctive, and reciprocal role theory has suggested that sons may look to their fathers as a role model for the development of masculine traits (Balswick, 1988), while daughters may learn feminine behaviour by interacting with and complementing their father's masculine traits (Johnson, 1998). These relationships may be further complicated by the demands that cancer treatment places both on the sick child and the father, and the individual ways in which both parties respond to these demands.

Changes in family dynamics resulting from the cancer diagnosis were also challenging to a Father's role. According to family systems theory, changes in one family member can affect all family members (Wright & Leahey, 2000). In the context of cancer, a child's diagnosis may have led to changes in the way attention and energy was distributed across the family: instead of equalising attention across children, parents tended to focus on the sick child. As a result of this increased focus on the sick child, and an awareness of the hardships of treatment, fathers often found it difficult to set and maintain boundaries for the child with cancer:

In the first month, things just really went to custard, really. 'Cause we felt so sorry for Matthew, he had no boundaries around him really, he just went feral. And we were sort of scared about losing him, that we let him have everything, but it actually wasn't the right reason to do that, should have kept the boundaries on him, just treated him normally. *Jack*

I know we are giving him more stuff to compensate for him not being able to go out. So he's got new tablets this week, and new headphones, and all his new movies are on it, and that's to keep him happy while he's in hospital,



because he can't go out and go shopping or go to classes or anything like that. So we're compensating that way. So maybe we're trying to overcompensate on a few things. And letting him off on the feeding and letting him have his dinner on the couch, because he's too tired to go and sit up straight. I suppose we are letting him away with quite a bit actually, thinking about it. He doesn't have to go to bed at exactly half past seven like his brother does. *Ryan*

Fathers felt "so sorry" and were "scared about losing" their child with cancer that they often "overcompensated" by relaxing boundaries and giving their child privileges they otherwise might not have. This is consistent with previous research which has also suggested that parents struggle to set limits for children with cancer (Björk et al., 2009). Fathers in this study also found it difficult to re-establish boundaries post-treatment:

I'm not hard on him, you know. I think he's been through enough. For myself, I think it's just to support him and make sure that he's enjoying life ... I think I spoil him a little bit, but my wife would be a bit harder, you know ... So I think I'm a bit soft on him. *Luke*

She's always been a Daddy's girl ... We've been pretty generous, what she wants, she gets. Not off the back, she has to do chores still, and bits and pieces. But I will go and buy her bits and pieces and clothes a bit more openly. But then it makes me feel mean when I put my foot down and say no, it's not going to happen today, and she gets upset. But you just do it in a way that weans it off. She's always, in that eight months, had her way, part of the healing process, she's grown up, she's 12 but she's really 15 ... So we just bring her more into alignment with the other kids. But if anything's going to happen, she always gets it first ... I can't really differentiate except she's gone through a hard life. *Robert*

Fathers described acting in a more "generous" and "soft" way towards their child who had experienced a "hard life" because of the cancer treatment. However, Robert realises the need to bring his daughter "more into alignment" with her siblings post-treatment, although he acknowledges he still has the tendency to feel "mean" for saying no to her demands and to give her privileges "first". The imbalance in family dynamics created by the focus on the child with cancer during treatment was a significant challenge for Fathers both during treatment and post-treatment, as they tried to restore balance by equalising attention. One father in particular found it difficult to shift back to pre-treatment family dynamics because of his daughter's reaction:

During the treatment she was my baby and she was the one who was in need and she pretty much had mine and her mother's undivided attention. When her treatment ended I called it the "girl normal syndrome" – she went to "girl normal" and she started to act up to get our attention or my attention, mainly because I could relax and start sharing it among the other siblings. I found it quite upsetting – she went through that cut herself period. Some people tried to tell me it's because they've got other pain inside their heads where they need to hide it through cutting themselves whereas in Jessica's case, she needed something for us to focus on and she did admit that she wasn't doing it for any other reason than she missed the attention. *James*

James describes finding it "quite upsetting" when his daughter Jessica began to "cut herself" because she missed having the undivided attention of both her parents that she had enjoyed during the three years of her leukemia treatment. Not only was this a difficulty in James' relationship with Jessica, but it also challenged his attempt to re-establish relationships and share attention amongst his other children. It is evident that in their roles as Fathers, Cancer Dads must not only deal with challenges pertaining to the sick child's transition back into normal family life, but also need to be aware of the needs of siblings throughout the cancer journey. A number of Fathers described awareness that their other children had missed out during the cancer treatment period:

We did the wrong thing. We should have equalised attention. And in the first year or so we didn't. And she lost a little bit. And we've made some gains and that. But she's independent now, you know, she's a fifteen-year-old girl, so it's hard to gauge what your relationship with your kids are, so full of drama and things like that. But she missed out, there's no doubt about that. And we've tried to make it up to her. *Jack*

You weren't there as often for them. They'll see you as unreliable. It never broke to the point where my children didn't want to listen to me or be seen with me ... I'm still the father no matter what. It did affect it. You try to promise them things and then you can't fulfil because suddenly Jessica gets sick and you've got to run off. They probably had a little resentment as such but then again, they always saw the big picture. We always kept our children fully informed, in the loop, nothing was hidden from them. *James*

Siblings of the child with cancer often "missed out" on time and attention from their Father due to the focus on the child with cancer and the demands of their

treatment. For fathers like Jack, the realisation that they should have “equalised attention” came after a year of treatment, when he realised that he had lost precious time with his daughter. James also realised that his relationship with his other children had been affected by his involvement in his daughter’s treatment. The intensive and unpredictable nature of treatment meant that he often appeared “unreliable” to his children and was unable to fulfil some promises to them. James also struggled with the capacity to share his emotional energy with his other children during cancer treatment:

The biggest change came when the physical treatment ended. She was my focus for the whole period, trying to split yourself to give attention to your other children was a bit hard. They all had their emotional needs. The way I feel it, most men can really only focus on one emotional need at a time. Others are probably capable of more. *James*

James’ experience is consistent with research suggesting that only when the child with cancer’s needs were met, could the focus move to other members of the family (Björk et al., 2009). A recent systematic review of the psychosocial adjustment of siblings of children with cancer reported that a significant proportion experienced negative emotional reactions and poor quality of life across social, family and emotional domains (Alderfer et al., 2010). While some Fathers in this study struggled to find the time and emotional energy to engage with their other children during cancer treatment, others were aware of the adverse effects that the cancer may have had on their other children and made a conscious effort to spend one-on-one time with them:

We have made quite a large effort, a big effort with Bradley to spend a lot more time with him one-on-one, rather than a group thing. To show him he’s not being left out ... I go swimming with him on the weekends, I take him bush walking on the weekends. My wife takes him out to a café on the weekends and has her time out with him, Bradley-time type thing. But he’s definitely got quite anxious ... He’s five in December and he started wetting the bed again. Which is not a good look, especially when he sleeps with us ... We’ve tried to spend that time with him to give him that one-on-one stuff, and he’s definitely enjoying that. *Ryan*

Ryan recognised that the affects of cancer were not isolated to his oldest son, but that his youngest son Bradley had also been affected by the cancer-related changes in family life and was becoming “quite anxious”. As a result, he made a “big effort” to make sure his youngest son was not left out and enjoyed quality “one-on-one” time with both parents. However, Andrew struggled to manage family dynamics during treatment

and reported instances of sibling resentment because of the extra privileges and attention enjoyed by his sick child:

Occasionally Melanie will have a meltdown or whatnot and she'll really spit her dummy out and everything else. There are occasions when we get worried about her. We think some of it is because of what's actually transpired with Alex. During the course of the treatment we had Melanie seeing a child psychologist on a couple of occasions and then we didn't know but we thought she might be putting symptoms on to try and get some of the stuff that Alex was getting. She's had instances where, "You don't love me, I'm going to leave home." I don't know whether it's because she's a girl or whether it's because she's going through that age or what but she swings like you wouldn't believe. *Andrew*

Andrew struggled with his daughter Melanie's reaction to the extra attention and bribes given to her brother during his cancer treatment. He was "worried" because she seemed to be quite jealous and resentful of her brother to the point where she "might be putting on symptoms" to get attention. She also "really spit her dummy" and threatened to leave home because she felt unloved. Similarly, James talked earlier about how his other children may have had a "little resentment" towards Jessica. He tried to manage this by keeping his other children "fully informed" about Jessica's treatment so that they could be aware of their sister's needs and the "big picture".

It seems evident that it is important for Fathers to be aware of the effects that cancer may have on the entire family system, and to be careful not to ignore or alienate the needs of siblings. It may also be appropriate to keep older children informed of what is happening, so that they understand why the sick child may have different privileges and attention during the treatment phase and do not mistake a difference in parenting style for deliberate favouritism or a lack of love.

## **Husband**

While balancing numerous other roles relating to their sick child and other children, Cancer Dads also had to be aware of the ongoing importance of their role as Husbands to their wives. Many Cancer Dads found themselves re-negotiating their relational role as a Husband following their child's diagnosis with cancer, as the stressful reality of treatment put a strain on their marital relationship:

We've both put on a lot of weight, comfort eating. She's drinking a lot more. I don't drink, or I probably would be ... She's got a lot of anxiety too. I

suppose as a male, we don't show that side of things. And she gets a bit pissed off with it. And I can see why the divorce rate is so high. You have to bite your tongue because we're tired, we're grumpy, we've both put on truckloads of weight. We're eating the wrong foods, we're not sleeping properly, we lash out. It would be quite easy to walk away and get divorced. I think there's about a 30% divorce rate, just from the stress. *Ryan*

To say it didn't put a strain on anything would be a lie. Not only are you thinking about your child, your other children, you're also thinking about ... what would happen if she died? How would our relationship change then?

*James*

The intensive nature and demands of cancer treatment made it difficult for some Husbands in their relationship with their wives, as both had to manage significant stress, anxiety, sleep deprivation, and the uncertainty of their child's future. Husbands also struggled to spend one-on-one time with their wives, as care of the child with cancer was the dominant focus:

Some genius, about two weeks after Charlotte got diagnosed, told us that, I can't remember the number exactly, "Be careful and look after each other because 64% of the people whose kids are diagnosed with leukaemia get divorced". That was a really great thing that someone told us. For the best part of two years, half the time we didn't sleep in the same bed and we were Charlotte's co-ordinators and we'd see each other for 10 minutes a day or half an hour if we didn't have stuff on ... That was really hard times for a marriage but it wasn't about us, it was about her. We were able to get through. *Dan*

I suppose you've got to think about, we're so tired so the intimacy goes out the door. We now have a child sleeping in our bed, so that affects that as well. So it's pretty full on. It has changed our relationship. I think we work more together. But we are actually physically trying to have more 'us' time. So it's just a matter of juggling all that stuff. But you've got to really work at your relationship. That's a real chore. *Ryan*

The practical necessity that one parent must stay with the cancer child in hospital at all times meant that Husbands and wives often went a considerable amount of time without spending quality time with each other or sleeping in the same bed. Dan felt like his marriage relationship was on hold, as it "wasn't about us, it was about her". Furthermore, both Dan and Ryan acknowledged that the stress and difficulty of cancer

treatment may lead to a serious breakdown in the marriage relationship for some couples. The struggle to spend time together and prioritisation of the sick child over the marriage relationship during treatment was also reported in a study by Neil-Urban and Jones (2002a). The lack of quality time available for couples during cancer treatment as reported by Neil-Urban and Jones (2002a), and the acknowledgement that stress can lead to a significant breakdown in the marital relationship, makes a strong case for the importance of Husbands making conscious effort to “really work” at their relationships with their wives.

Husbands also reported an increase in conflict with their wives during the cancer treatment period:

It's not the easiest, you get more angry with each other, but it's not a real world you're judging yourself in, there are probably other things in the background that probably upset your mind a little bit more as well. *Robert*

The stress has been a big problem. We've argued and fought more, only because of the stress, and we know that it's because of the stress. We've grumped more because the stress. We know that. We're aware of things and we still even now will fly off the handle but we know why. We've just got to try and work it out. But, yes, we do care for each other immensely and we know of families that have flung apart because of it and it's easy to see why, but this is when you need each other most, and your family, if you're lucky enough to have a close knit family, which we do, and friendship. *Max*

A number of fathers reported an increase in arguments with their wife, which they attributed to the “stress” of caring for a child with cancer. Robert explains that “it's not a real world you're judging yourself in”, drawing attention to the abnormal, stressful environment of the cancer world that the marital relationship is subjected to. The cancer treatment period also heightened an awareness of differences within the relationship:

We've had dark moments because I think because we cope differently. She would talk to Mum or friends or whatever. I kind of keep it to myself. She may think that I don't care but it's just the way I cope. I do something different, I like quiet, I like to think but she may think I'm avoiding it. I always say I think we've been through heaps and I think we will come right. I think what happened was we just focused on Ryan and didn't focus on each other. It affected our relationship; we went through a bit of a hard time. I



think we need to build up some time together ... We've had counselling at Starship – all of us – me, her, and Ryan. *Luke*

Luke experienced some “dark moments” in his relationship with his wife and attributes this to differences in coping styles and a lack of focusing on each other. Luke recognised that they needed to repair their relationship through counselling and spending quality time together. While most fathers emphasised the strain on their role as a Husband during the cancer experience, many also saw the experience as foundational to finding a new strength as a couple:

I can't see myself without her and she's the same. But there was an awful lot of strain put on whilst Aaron was going through his treatment and most of it was, I wouldn't say our making, but it was our making, if you understand what I'm saying. *Andrew*

We've always talked, but we talked a lot more. Yeah, and we confided in each other. If she was upset, I'd listen to her more. Suppose when you've been married twenty-odd years, you know, you can get to a point where you think 'Oh God, here we go again' but no it wasn't any more. She was genuinely hurt, really hurt, your son's possibly dying. You know, I think it's helped our relationship. In that warped sense, alright. I'd rather have not been there. But it's there, can't change it. *Jack*

For fathers such as Andrew and Jack, their relationship with their spouse was strengthened by being able to get through the mutually challenging experience of cancer together. While Andrew does not in any way downplay the hard times they experienced, he recognises that in the end, getting through them together was their “making” as a couple. Similarly, Jack realises that the shared cancer experience had increased the quality of communication in his relationship with his wife and allowed him to be more empathic towards her feelings. David and Caleb also reported positive outcomes in their marital relationship as a result of the cancer:

She's as strong as an ox, in a nice way. And we just knew that we had to stay united on this thing and work out ways through, work your way through it. It was one of those, I think it's Winston Churchill that said, “when you go through hell, keep going” ... I just think it made us closer as well, in normal sorts of ways. We needed each other as rocks. *David*

It hasn't made our relationship any worse, it's probably strengthened it, I think, to be honest. We had a good relationship anyway. A lot of the silly things that you think about and you worry about, you really realise that

they're not important, so you cut a lot of the distractions out of your life and any silly insecurities you might have, they really become minor and not worth worrying about or focusing on. So, that really helps. I think your focus becomes a lot clearer on outcomes. *Caleb*

David experienced a closer relationship with his wife as a result of the cancer experience. They “needed each other” to get through and made an effort to be “united” in working their way through the crisis. By calling his wife “as strong as an ox” and his rock, David is able to convey the strength of support his wife was able to offer him during the cancer period. Other studies (e.g. Jones & Neil-Urban, 2003) have also suggested that fathers of children with cancer who were able to express their emotions to their wives were able to find strength and comfort through the sharing of difficult experiences. Caleb also experienced a strengthening in his relationship with his wife, and a positive change in perspective: he was able to cast aside “distractions” and “silly insecurities” in his marital relationship and focus on the bigger picture. It seems evident that the marital relationship can be a significant source of support for fathers, when both Husbands and wives are able to communicate well, spend considerable effort working on their relationship, and share the burden of care for the sick child and other children.

### **Family Man**

Throughout their child's cancer treatment, fathers also experienced challenges and changes in their role as the lead male of the family unit. Following a child's diagnosis with cancer, fathers often became more aware of their role as a Family Man, and the importance of family:

We're a close family anyway, you know. We have our ups and downs but that's a normal family life, isn't it? You've all got to pull together; if you don't it can be a nightmare. *Jack*

It was like glue. And we just all rallied around, including Tim and Rebecca, our two other children. And I think we became quite insular. *David*

Without a family support system, Jack suggests that the cancer experience can be a “nightmare” and that it is important for all family members to “pull together”. David's family also “rallied around” for support, and he described the cancer experience as being like “glue” that held them together. As the entire family system is affected significantly by the cancer diagnosis of one child, it seems crucial for the entire family to pull together. To facilitate this increased support and closeness, fathers described a shift in priorities and work-life balance towards their role as a Family Man:

I think our family relationship's really changed a hell of a lot. I think as a family we probably got closer and because now our focus really is on the family unit as opposed to maybe the other stuff you were focusing on before. My work's become a lot less important. I'm not very materialistic anyway but some of those things that you think about, they're just not important. We like camping; we're going to head off down the South Island for our first holiday on Friday as a family. *Caleb*

Guess you've got to do the best for the family. So work very hard but I spend much more time now at home. I used to get home from work, open up my laptop, start skypeing with China, and then from 8 o'clock onwards, I'd be skypeing Europe and finishing at 1 or 2 o'clock in the morning. And be off to work again early in the morning. Now I go to work at half past 8 in the morning, maybe 9 o'clock sometimes. I don't turn my laptop on until 8 or 9 o'clock at night now. You know, spend more time with the children. So you learn to do that. *Ryan*

Both Caleb and Ryan reported a shift in priorities away from work and towards spending more time with their children. Caleb describes his increased focus on the family unit and being able to let go of less important things he may have thought about in the past. Ryan similarly feels that the cancer experience has taught him to spend more time with his children and focus on what is "best for the family". There is a sense that they both have an increased appreciation of family and their role as a Family Man as a result of their child's diagnosis with cancer. The experiences of Caleb and Ryan are consistent with the reports of fathers in a recent study (Nicholas et al., 2009) who felt an intensified responsibility to care for and keep their family together during cancer treatment. Another father in the current study, Robert, also talked of learning about the importance of spending quality time with his family as a result of the cancer diagnosis:

But learned from day one, it's not about the quantity of time, you have to use quality of time. So you come home, you don't sit on the couch in front of the TV, you know, we'd jump in the boat and go out fishing or we went down to the beach, or went down to the farm, or went and did something. *Robert*

Robert highlighted a key learning experience in his role as a Family Man – not only was it important to spend time with his children, but it was important to spend quality time interacting with them. Fathers also reported giving up their own sports or hobbies in order to spend more time as a Family Man:

I shoot for a sport. I've had to give up shooting this year. So I haven't touched my guns since January. You've got to give it up. I sold two of them, to pay for some other stuff. I'd love to get back into my shooting and stuff like that, but I just can't, don't have the time. And I've just had to blank that out of my life for this year at least and change my role so that we can look after that side of things. And you've just got to do it. *Ryan*

I was actually training for a triathlon, half iron man so that was going to be in January. At that time I was pretty fit, I was only six weeks away from a half iron man so I had been training a lot. We knew financially it was going to be a struggle so paying 20 bucks a week for a gym membership and there wasn't enough time to carry on the training so flagged that and flagged the gym membership. *Dan*

Ryan and Dan both gave up their own hobbies during their child's cancer treatment as they chose to prioritise spending time with their family over pursuing their own personal interests. In Ryan's mind, putting his sick child and family first was non-negotiable: "you've just got to do it". Furthermore, both Family Men made financial sacrifices: Ryan sold two guns to pay for family expenses and Dan gave up his gym membership so that it would not be a financial burden to his family. Fathers of children with cancer in a study by Chesler and Parry (2001) also reported making an effort to spend more time with their family and less time on their own or stressing about work-related issues.

For many fathers, the uncertainty and shock of their child's diagnosis with cancer was a catalyst for an increased commitment to their role as a Family Man and desire to spend more quality time with their children. Many Family Men reported an increased awareness of the vulnerability of their children and of the important place they held in their lives:

It's made me appreciate him more really. The fact that he could be gone. You know, even now, we still get scared. Just, it's like this spectre that always looms over you. Never goes really. You know, just before Christmas we got told he may have a heart defect as a function of the medications he'd had. Oh my God, here we go again. So if the cancer doesn't kill you, the medication might. It turns out it was a false positive, or a false result, it was a poor reading ... So there's always something there, so makes me appreciate him more, and the family. *Jack*

When it's your child, they're your future. Your parents are your parents. When you actually fly the coop you don't need them. You might need them occasionally, "Can you give us a hand?" Parents are fantastic but in some respects when they've gone, flown the coop, you're making your own way in the world. And you're their future. So, when it's your children, they're your future. They are; what else are you going to leave? There's nothing else you are going to leave – photos but they'll pass in time. The only legacy you've got is your children, your grandchildren, your great-grandchildren going forward. That's the only legacy you'll ever leave. You won't leave anything else. *Andrew*

Jack reflected on the uncertain future his son faces and referred to the fear of the cancer returning as the "spectre that always looms over you". While fathers were grateful for their newfound appreciation of their children and family, it often came with a sense of loss and sadness over their child's suffering and precarious condition. Andrew also has an epiphany about the central place his children hold in his life: they are his "future" and the "only legacy" he will leave. As a Family Man, this realisation spurs him to make the most of whatever time he has left with his children, and to invest in them as his "future".

Overall, it appears that fathers in this study discovered a new appreciation for their children and family as a result of their child's cancer diagnosis and the uncertainty that brought. As a result, many fathers made a conscious effort to shift their priorities from their own interests and work to spending more quality time with their families. Fathers often described the lessons they learned about the value of their role as Family Man as positive outcomes of their cancer experience.

## **Summary**

Following their child's diagnosis with cancer, Cancer Dads re-evaluated and refined their relational roles as a Father, Husband, and Family Man. In their role as a Father, an increased focus on the sick child had to be balanced with attending to the needs of the other siblings. A number of Fathers struggled with maintaining boundaries for their sick child, meeting the needs of siblings, and equalising attention among their children post-treatment. The cancer treatment period also represented a difficult time for the husband-wife relationship, as ongoing stress, sleep deprivation, a focus on the needs of the sick child, and limited time together put a strain on the marital relationship. However, a number of fathers in the role of Husband also reported an overall

strengthening of their marriage as a result of the shared cancer experience. Finally, fathers came to a greater appreciation of their role as a Family Man through the crisis of cancer, and set aside other priorities so they could spend more time with and invest in their family.



## Chapter Seven

### Conclusions

This chapter discusses the main findings of the narrative analysis, significance of the study, and practical and clinical implications for health professionals or support organisations working with fathers of children with cancer. Limitations of the research and suggestions for future research are also explored.

#### **Summary of Findings**

This study explored fathers' accounts of their child's cancer. It did this through an analysis and discussion of the ways in which they embodied different aspects of the experience of being the father of a child with cancer. Analysis was focused around the central role of Cancer Dad, as following the initial diagnosis, fathers realised they had become a Cancer Dad and had to negotiate a period of shock and devastation as they grappled with the serious nature of their child's diagnosis and the uncertainty of their child's future. There were four main ideas which came out of an exploration of what it means to be a Cancer Dad: taking control, finding strength, juggling responsibilities, and managing relationships. Within each of these four ideas, there were subsidiary roles that fathers experienced.

Firstly, Cancer Dads commonly described experiencing a desire to take control of their child's situation. In the role of Decision Maker, fathers attempted to regain control by making decisions about their child's situation. Similarly, when taking on the role of Active Advocate, fathers shared the importance of being well-researched and assertive so they could stand up for their child's best interests. Finally, fathers reported a re-established sense of control by taking charge of the practical areas of their child's life and enforcing infection control and adherence to treatment in the role of Practical Policeman.

Secondly, Cancer Dads shared about the importance of finding the strength and inner resources that they needed to support themselves and their families through the trials of treatment. Fathers reported feeling pressured to take on the role of Emotional Rock, masking their own emotions in order to provide stability and support for their family. Fathers emphasised the importance of finding a safe or private way to vent their own emotions, rather than bottling them up and leaving them unresolved. Fathers also reported feeling disconnected and misunderstood, and some decided to move into the

Lone Wolf role. Although some fathers described feeling reluctant to ask for or accept help from others, those that did accept help from friends and family found it very useful.

Thirdly, Cancer Dads shared their experiences around the challenge of juggling their responsibilities. Some fathers acting as Breadwinners found it difficult to meet work obligations and provide financially for their families during cancer treatment. Two fathers in particular faced significant challenges from their employers in their role as a Breadwinner and suggested the importance of seeking workplace advocacy. In the role of Caregiver, fathers often felt challenged by the expectation that caregiving was traditionally the mother's responsibility and at times reported feeling undervalued and misunderstood by hospital professionals. Nevertheless, fathers described valuing the opportunity to be involved and spend time with their sick child as a part-time or primary Caregiver.

Finally, Cancer Dads described the struggle to manage their relationships during the cancer journey. Due to the intensity of treatment, fathers reported that they spent a lot more time with their sick child which led to positive changes in that relationship. However, fathers also reported struggling to maintain boundaries for the sick child, and suggested the importance of being fair among siblings and putting effort into relationships with other children from the early stages, as otherwise they would be likely to feel left out. During cancer treatment, stress, sleep deprivation, lack of quality time, and focus on the sick child put considerable strain on many Husbands' relationships with their wives. However, by supporting their wives through the difficult times, many Husbands found that their relationships were strengthened overall, and they had a greater appreciation for each other. Cancer Dads also reported prioritising their role as Family Man and spending more time with their children as a result of their cancer experience.

Overall, findings and discussion indicated that social constructions of masculinity and fatherhood shaped and underpinned fathers' accounts and were at the heart of many of the challenges and experiences shared by fathers across their child's cancer journey. Findings were consistent with trends in the literature which indicate a change in cultural practice towards an idea of 'involved fatherhood' (Cosson & Graham, 2012; Dempsey & Hewitt, 2012) – evident particularly within the role of Caregiver. However, it was also apparent, as suggested by Yarwood (2011) and Palkovitz (2002), that breadwinning remains a dominant and valued duty of fatherhood and paternal masculinity. Furthermore, the dominant discourse of New Zealand masculinity – the strong, stoic 'Kiwi bloke' – was strongly evident within fathers' attempts to find and give emotional support within the roles of Emotional Rock and Lone Wolf, and the

expectations they perceived to be upon them, despite the fact a number of fathers felt that they did not fit naturally within this discourse of masculinity. Ideas of leadership were also strongly aligned with being a man and a father within the roles of Decision Maker, Active Advocate, and Practical Policeman. It seems evident that social constructions of masculinity and fatherhood underpinned fathers' accounts and reconstruction of their roles and identity as a Cancer Dad throughout this narrative inquiry.

### **Theoretical Significance**

This study has made an important contribution to the literature in a number of ways: through its use of roles as a means of understanding the complexity of fathers' experiences during their child's cancer, through its inclusion of objects and recognition of their significance as narrative devices which can enrich the research process, and finally through its exploration of masculinity and fatherhood and how fathers understand their place in the world throughout the challenges of their child's cancer.

Firstly, this study has provided a significant theoretical contribution through the use of roles as a narrative framework and as a means of making sense of fathers' experiences of their child's cancer. The use of roles works well as it allows the analysis to capture the ways in which a narrator chooses to shape his narrative and chooses to portray himself as a character within his story. Furthermore, an analysis of roles recognises the influence of societal expectations and discourses on the ways in which fathers respond to the challenges of their child's cancer treatment. Through an understanding of the ways in which fathers construct themselves within the central role of Cancer Dad, the reader is able to better understand the shift that fathers experience as they move from their former identity as a 'normal' Dad to their new identity as a Cancer Dad through the life-changing moment of their child's diagnosis with cancer. Similarly, through exploring the ways in which fathers constructed themselves within the ten subsidiary roles of Cancer Dad, the reader is able to better grasp the breadth and depth of the challenges, tensions, triumphs, and emotional-ups-and-downs that fathers experienced during their cancer journey. This study has provided an in-depth and rich account that does justice to the complexity of fathers' experiences, and in doing so, has made a significant contribution to an area of the field where such studies are rare.

Secondly, this study has been important in the way it which it has incorporated objects of significance into the interviewing and analysis process. As argued by

Sheridan and Chamberlain (2011), visual methods can deepen and enrich the research process. Within this study, objects have been used by fathers as powerful narrative devices which have brought to light stories which otherwise might have been untold; brought focus, depth, and clarity to past memories; and allowed fathers to reflect upon or justify their actions. Objects were also used by fathers to engage the senses and add another dimension to their narratives. Finally, at times objects caused a shift within the interviewing process through their confronting and emotionally provocative nature. By eliciting an emotional reaction from the interviewer, fathers were able to use to objects to bring the interviewer alongside them through an emotional experience and sense of shared understanding. Overall, the inclusion of objects within this study has encouraged narrative talk, increased the intricacy and depth of narratives shared, prompted reflexivity by participants, and added to insights and interpretation by the researcher.

Finally, this study is important because of its exploration of ideas about fatherhood and masculinity and the insights it has uncovered about how fathers of children with cancer understand their place in the world. Throughout the analysis of fathers' roles, ideas about masculinity and fatherhood are prominent and shape the ways in which fathers respond to challenges within each of their roles. Within each role, there was a tension between what fathers' perceived society expected of them as a father and a man, and the reality of their experience of their child's cancer. For example, within the role of Decision Maker, fathers felt the pressure to provide leadership and sound decisions about treatment for their families, as they viewed decision-making as an area of traditional strength and part of their responsibility as the father. However, while previously fathers may have felt at ease making decisions in business and other areas of their life, many fathers felt ill at ease and anxious about the long-term consequences of the decisions they felt responsible for during their child's cancer treatment. This uncertainty and anxiety may have challenged their identity as a father and man who makes decisions. Similarly, the roles of Active Advocate and Practical Policeman, which are traditionally seen as strengths of masculinity and fatherhood, were challenged by the reality of cancer. Fathers attempted to live up to expectations that they would take control, be assertive, and take care of all their child's practical needs, but were challenged by the lack of control they felt over many areas of their child's health.

Fathers' ideas of masculinity were also challenged within the role of Emotional Rock. While fathers may have had previous experiences of being emotionally stable and in control, the reality of their child's suffering, stresses within their family, and their

own emotional responses, seemed to lead many of the fathers to question their masculinity as “big hairy men don’t cry”. Fathers struggled and felt as though they could not live up to traditional ideals of the man that does not show his emotions and stoically supports his family (Phillips, 1987), and seemed unable to find a model of masculinity which directed them in how to process the strong emotions they were experiencing during their child’s cancer while still living up to society’s expectations. Similarly, within the role of Lone Wolf, fathers’ perceptions of men as self-sufficient and independent led them to struggle to ask for or accept support.

Ideas about masculinity and fatherhood were also pervasive throughout fathers’ experiences of juggling the roles of Breadwinner and Caregiver. While fathers seemed to value the opportunity to have greater involvement in their child’s care, fathers’ experiences of their role as a Caregiver was still in many ways still shaped by traditional assumptions about masculinity and fatherhood. As caregiving is not generally seen as a traditional strength of masculinity or fatherhood, some fathers felt as if they were being overlooked and undervalued when they stepped into the role of Caregiver.

Finally, the ways in which fathers managed their relationships during their child’s cancer were also shaped by ideas about masculinity and fatherhood. Following their child’s diagnosis, Fathers needed to work out what it meant to be a Cancer Dad and learn how to adequately care for the complex physical and emotional needs of their sick child, while also caring for their other children. Fathers grappled with the expectations of their role as the man and disciplinarian of the house; as they also experienced a strong desire to loosen the boundaries for their sick child due to the hardships they were undergoing. Similarly, fathers had to redefine their place as a man and a father within their relationships as a Husband and a Family Man, in light of the stresses and changes they experienced in family life during their child’s cancer.

In summary, this study has provided significant insights into the ways in which fathers of children with cancer understand their place in the world and grapple with challenges to their constructions of masculinity and fatherhood. Furthermore, this study has shown how entrenched traditional concepts of masculinity and fatherhood can be, and has explored the ways in which their child’s cancer may lead fathers to challenge, reform, and reshape their ideas about masculinity and fatherhood.

## Ideas for Change

The findings of this study offer a detailed understanding of the experiences of fathers of children with cancer that can provide us with valuable ideas for changes that could take place in practical and clinical settings. It was each father's intention that his participation in this study, firstly, would be used to help other fathers of children with cancer in their individual journeys, and secondly, would be used to inform a greater understanding of how people, particularly health professionals and community support workers, might best respond to and support fathers during this difficult time.

Firstly, the current study highlights the benefits that may occur when health professionals and community workers support fathers in being actively involved in their child's care. Within the field of paediatrics, May (1996) suggests that fathers tend to be the 'forgotten parent'. Health workers in the oncology field may need to be mindful of cultural beliefs and assumptions about parenting and actively encourage fathers' involvement in their child's care from the beginning. More specifically, it may be helpful if health professionals invite the father to attend the initial assessment and information session and let him know that his input is welcomed and valuable. Ware and Raval (2007) also suggest that it is important to provide follow-up after the initial diagnosis in order to provide fathers with support and the opportunity to discuss implications of diagnosis and treatment options. Through taking the time to give fathers the information they need, staff may be able to support fathers in a way that aids their sense of competence and control, facilitating their role as a Decision Maker, Active Advocate, and Practical Policeman for their child. Furthermore, helping fathers to feel at home in the hospital and creating a safe space in which fathers can ask questions and express their concerns may help to alleviate additional stresses and uncertainty that may have otherwise had a negative impact on fathers' wellbeing.

Secondly, findings from this study suggest that some fathers in the roles of Emotional Rock and Lone Wolf struggled to find a safe space to express their emotions about their child's cancer, and often felt isolated from friends and social supports. Most fathers in this study chose to hide their feelings from their family and reported they felt like few people understood what they were going through and were able to support them. It may be helpful for health professionals and community support workers to affirm that fathers do matter, that they have emotions, and need caring support. Following diagnosis, fathers could be made aware of the different avenues available to them for support, for example, through the hospital, cancer charity organisations or through other community organisations, in a way that normalises and encourages support-seeking. It is also useful to acknowledge that there is no one supportive



initiative that will address the needs of every father. Each father has individual needs, a unique way of processing his child's cancer journey, and may choose to access varying levels of support. As Caleb puts it: "Every dad's going to be going through a different journey in their own mind." While some fathers in this study engaged readily with all supports available, other fathers felt that they did not require assistance or that available support services were not right for them.

Several fathers suggested that connecting with another father of a child with cancer, who was further through the journey than they were, would be helpful. Fathers indicated that talking to another Cancer Dad could be particularly helpful during or at the beginning of their journey:

The best thing I could've got at the beginning was someone sitting down who's been through this and saying, "This is what it looks like for you, this is what the next three months are going to look like, this is what the next six months are going to look like." *Caleb*

Sometimes it's easier to take advice from a likeminded father than from some person saying, "I'm such and such". *James*

In addition, organising and advertising times that fathers of children with cancer can meet and support each other throughout the cancer journey may provide an opportunity for fathers to feel understood and offer support to one another. As a number of fathers in this study reported struggling to express their emotions, a more relaxed setting where the day is focused around another activity, such as fishing, with room for talking as fathers become more comfortable about opening up, may be appropriate. One father was also an advocate of parent or family outings, as he suggested that fathers were more likely to talk when their wives were present.

Fathers may also benefit from the opportunity to read about the experiences of the twelve fathers who participated in this study through a medium such as a brochure (see Appendix E). Sharing a summary of the findings and key learning points from this study may help fathers, particularly those at the beginning of their journey, to be more aware of and prepare for challenges they may encounter throughout their child's cancer treatment. Fathers may benefit from information and support, not only around the medical journey, but the emotional journey:

What you get given is a book from the hospital with a load of stuff in it but, again, it tends to be about the medical journey. I think it's the spiritual one that screws you up, not the medical one because that's fully in control and that's well documented, well understood, well managed, protocols around it.

But the emotional journey isn't well understood and I think everybody would be learning and relearning every single time and it's a well-known experience because lots of people have gone through it already. *Caleb*

Access to a brochure which describes the emotional journeys and discoveries of twelve fathers, as explored in this study, may be especially helpful to fathers who may not feel comfortable talking to anyone, but want to prepare themselves for the emotional rollercoaster ahead. A brochure may also appeal to fathers who prefer problem-solving strategies over emotion-focused coping, and is consistent with Ware and Raval's (2007) study suggesting that more active and problem-solving focused interventions may be more helpful than emphasising exploration of emotions for fathers of children with cancer.

In addition, it appears that many fathers of children with cancer grappled with perceptions that they would be perceived as less masculine in the eyes of those around them if they were emotionally expressive. This may be fuelled by the New Zealand stereotype of the 'kiwi bloke' who is strong, manly, and does not show his emotions (Phillips, 1987). This hyper-masculinisation often leaves little room for alternative conceptualisations of masculinity (Campbell, Law, & Honeyfield, 1999) and can leave fathers of cancer feeling alienated if they do not conform to these expectations. The current study suggests that there needs to be a greater awareness and acceptance of alternative masculine identities that allow fathers to seek out support and express their emotions in a safe and healthy way - as one father eloquently put it, "big, hairy men cry too".

Thirdly, findings from the current study indicate that some fathers of children with cancer may benefit significantly from more advocacy in the workplace. While most fathers had sympathetic employers, a few fathers reported workplace discrimination, disciplinary meetings, or redundancy during their child's cancer treatment, which added significant stress to their role as a Breadwinner. It appears that fathers of children with cancer need employment arrangements that can guarantee ongoing income, job security, and advancement, while also allowing them the flexibility to meet personal and familial obligations. Ideally, these changes would take place at a workplace policy level, however, giving fathers the opportunity for advocacy from an outside organisation would also be a positive step forwards and may in part alleviate the financial burden shouldered by fathers in the role of Breadwinner.

Furthermore, one father suggested that access to budget planning and financial advice services could be very useful for a number of families, as many families lose an

income and accrue a number of additional expenses during their child's cancer treatment:

I think financial planning advice is important and I think the emotional and financial guidance to help families steer themselves through this is crucial otherwise you're left on a bit of a cliff where, "We'll look after your daughter but you're kind of on your own". Two income families is massive in Auckland because the average house prices screws people over, so helping those people navigate their way through will be helpful. Then looking at working with banks on trying to provide some relief – interest only mortgages or longer terms or whatever it was, so they don't end up in a big financial hole would be really useful. *Caleb*

While none of the fathers in the current study defaulted on their mortgages, several fathers told stories of other parents they had met through the hospital who had been unable to meet their mortgage obligations and had lost their houses. Advocacy in this area could make a significant difference for parents who are struggling financially, and could be a useful tool even for parents who are more financially stable. Moreover, it is vital that parents are informed of any financial assistance they can access, such as parking permits, petrol vouchers, or benefits, at the beginning of treatment so that additional financial stress is kept to a minimum for parents.

There are a number of benefits associated with improving the support offered to fathers of children with cancer. Fathers perform a number of important roles within the family during cancer treatment and their ability to manage these roles can directly and indirectly influence how well other members of the family cope with the ups and downs of treatment (Swallow et al., 2011). Cayse (1994) argues that supporting fathers is a crucial part of supporting a family in cancer treatment. Although fathers in this study showed resilience throughout many trials and challenges, the extent of the struggles they reported suggests the importance of providing greater support and resources. Fathers of children with cancer are recognised as a group that could be at risk of experiencing emotional distress and isolation during the treatment period (Nicholas et al., 2009) and it seems prudent that any steps that could minimise risk are taken.

A number of implications and ideas for change have been raised on the basis of interviews with the twelve fathers who participated in the current study. It is hoped that these suggestions might usefully be considered, by health professionals in the paediatric oncology field and organisations such as CCF, in order to address some of the fathers' concerns. Accordingly, CCF will be presented with a summary of findings

from this study and feedback specific to their organisation. In addition, a brochure (see Appendix E) has been created to provide a description of what to expect on the journey ahead from the perspectives of the twelve fathers in this study, with the intention that it will be made available to fathers of children with cancer through CCF. Finally, it is hoped that this study will create greater awareness of the need for alternative conceptualisations of masculinity and the negative effects that current perceptions may have on the wellbeing of fathers of children with cancer.

### **Limitations and Considerations for Future Research**

While this study has provided a unique discussion of the experiences of fathers of children with cancer, it has some limitations. Firstly, it needs to be understood that the findings of this study represent a snapshot of a group of twelve fathers within a particular time, place, and cultural context. As characteristic of qualitative studies, fathers may have shared different views or perspectives at other points in time or in other contexts. These fathers were reflecting on their experiences up to five years post-diagnosis and most had knowledge that their child was in remission. These factors are likely to have influenced what fathers chose to share during their interviews. In addition, the fathers who made up the sample of this study represented a group who were willing to talk and perhaps had a particular experience or viewpoint they wanted to share, and therefore the study may not have captured the breadth of experiences or opinions held by the broader population of fathers of children with cancer. Furthermore, the make-up of the sample was limited to fathers of children with cancer who resided in Auckland, the location of their child's treating hospital. Fathers who lived outside of Auckland and had to travel to a main centre for treatment may have experienced different challenges. The findings are likely to also be limited by the homogeneous make-up of the sample which included all heterosexual males, eleven of whom were married, and one who was divorced. This may have impacted the findings as the experiences of fathers or step-fathers from within blended families or non-traditional family structures were not represented within the sample group. In addition, while the sample included a broad range of socio-economic levels, there was limited cultural diversity, as only one father was from a non-Western and collectivist culture (Cook Island Maori). As mentioned previously, in collectivist cultures such as the Māori culture, values around the importance of family and extended family can be dominant (Durie, 1994), which may be reflected in the roles undertaken by those fathers.

Further research could expand on the current study in a number of different ways. Firstly, in response to the practical and clinical applications outlined by this study, it seems imperative that further research investigates fathers' experiences of support services, as well as exploring the complexities of how best to engage fathers in these services. Research in this area would help to ensure that any father-specific services are carried out in an effective way, and are able to engage a broad range of fathers of children with cancer. Secondly, studies in the future could focus on Māori perspectives and how Māori fathers experience their child's cancer journey in order to explore the impact that cultural values and Māori worldview may have on fathers' experiences of their child's cancer, and to facilitate a greater understanding of how best to support Māori fathers in their journey. Finally, future research could focus on the experiences and process of grief for fathers of children who passed away as a result of cancer, or experiences of fathers within blended families or diverse familial situations. Bereaved fathers may share stories and insights that are in some ways different to those discussed in the current study due to the unique experience of losing their child to cancer and may also need differing and more intensive supports following their child's death. Similarly, fathers within blended family situations may experience additional challenges when a child is diagnosed with cancer and further research could explore the ways in which this might be similar to or different from fathers from intact families.

### **Reflections as a Researcher**

One of the first pieces of advice I received about choosing a doctoral topic was to create a topic that I was passionate about, because three years was a long time to be bored! It did not take me long to decide that I wanted to focus my topic around the impact of cancer on the family, due to my personal experiences of journeying alongside my own mother, as she endured extensive treatment for breast cancer during my adolescence. While my own experiences gave me some understanding of the impact cancer may have on a family, nothing could quite prepare me for hearing the struggles, challenges, and triumphs experienced by twelve fathers of children with cancer who opened up to me. This project has not only challenged my intellectual mind, but has also touched my heart.

As a researcher, I have grown significantly throughout the researcher process. Right from the beginning, I decided to challenge myself and develop some new skills by choosing a qualitative design for my study, despite a solid background in statistics

and quantitative research. This meant that I initially floundered around trying to get a sense for the new paradigm I had placed myself under. However, it all began to make sense and I began to find my stride when the research interviews began. I was inspired by the unrestrained honesty with which fathers shared their stories with a stranger, and their hope that by sharing they would help those following in their footsteps. In the following weeks of transcription and analysis, I felt driven by a connection to these twelve, diverse fathers and a desire to share their stories well.

Working through the process of analysis over many months was both a frustrating and gratifying process. At times I was frustrated with the messiness that comes with real data about real people, and a constant need to critique and refine my analytic structure, but at the same time I was gratified by the richness and diversity of the data I had collected. As I dug deeper into each new role of fathering, I was excited to uncover similarities, differences, and new insights to share. Coming to the end of this process, my focus was on applications: how best could I use the greater understanding I had gained to inform interventions and services that supported fathers of children with cancer? It was with this, and my participants in mind, that I decided to design a brochure for fathers of children with cancer, based on the key insights of my research. In addition, I also released a summary of the results to participants (Appendix C) and key organisations involved with child cancer (Appendix D). Overall, my hope was that this study would be a valuable contribution not only to paediatric oncology literature, but also to fathers of children with cancer and those in practical and clinical settings that have the opportunity to support them.

### **Concluding Comments**

Through this study, I have connected with twelve fathers who chose to share their stories of heartache, desperation, hardship, triumph, and resilience with me. This study has made an important contribution to the literature by providing these fathers - the 'forgotten caregivers' (May, 1996) - with a voice, through using an analysis of roles to provide a meaningful portrayal of the challenging and complex reality of fatherhood in the context of childhood cancer. Furthermore, the inclusion of objects within this research project has brought to light stories which otherwise might have been untold; has brought focus, depth, and clarity to past memories; and has allowed fathers to reflect upon or explain their actions. Finally, this study has been significant in the way it has explored and challenged ideas of fatherhood and masculinity. This study has discussed the ways in which fathers grapple with their perceptions of their place in the



world as fathers and men in the context of the complex demands and challenges of the cancer journey. This study has highlighted how entrenched traditional concepts of masculinity and fatherhood are for many fathers, and has examined the ways in which fathers may challenge, reform, and reshape their ideas of what it means to be a father and a man in the context of childhood cancer.

This study has contributed not only theoretically, but practically, to the field of paediatric oncology. It was each father's intention that his story would be used as a tool to bring awareness, greater understanding, and more informed support to other fathers of children with cancer. Thus, this study has provided a practical understanding of fathers' needs and recommendations of the ways in which they can be further supported by professionals and those around them. Furthermore, a brochure has been produced which will communicate findings to future fathers of children with cancer by informing them about the emotional journey ahead. This brochure has been welcomed by CCF in New Zealand, who have signalled their intention to include it in welcome packs to families of newly diagnosed children and to refer to the brochure throughout the different stages of diagnosis and treatment as a way of connecting with and offering further support to fathers.

Overall, this study has provided an in-depth perspective into the challenges of fatherhood during childhood cancer and has made an important contribution to theory and practice to the field of paediatric oncology.

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## Appendix A

### CCF Cover Letter and Participant Information Sheet

#### CCF Cover Letter



Dear \_\_\_\_\_,

The Child Cancer Foundation is interested in an independent external research project; **The journey: A voice for fathers of children with cancer.**

The research project is supported and funded by Massey University and conducted by Sarah Whitton who is a Doctorate of Clinical Psychology candidate at Massey University, Albany. The project supervisors are Professor Kerry Chamberlain and Dr Angela McNaught, also from the School of Psychology, Massey University.

Why is this research being done?

The purpose of this study is to explore and generate further understanding of the experiences of fathers during their child's cancer journey. Currently, there is a minimal research in this area, as most studies in the past have focused on the experiences of mothers. It is hoped that findings from this study may help to inform and improve the way in which health care professionals interact with and provide support to the fathers and families of children with cancer.

Research like this can make a significant contribution to improving understanding and support services for families who are affected by childhood cancer.

CCF is supporting this research by distributing information sheets to potential participants and allowing the use of their meeting rooms for interviews.

Please take the time to read the information sheet included and to consider participating.

Yours sincerely,

A handwritten signature in blue ink, appearing to read "Maryanne Thomson", written over a horizontal line.

Maryanne Thomson

National Manager Child Cancer Services

Child Cancer Foundation

76 Grafton Road Grafton  
PO Box 152 Shortland Street  
Auckland 1140 New Zealand  
Tel 09 366 1270 Fax 09 377 9395  
[www.childcancer.org.nz](http://www.childcancer.org.nz)





## Participant Information Sheet

### Fathers of children with cancer: A narrative approach

#### Introduction

Are you the father of a child who has been diagnosed and undergone treatment for cancer? If so, I would like to invite you to participate in this study about the experiences of fathers during their child's cancer journey.

My name is Sarah Whitton and I am a Doctorate of Clinical Psychology candidate at Massey University, Albany. My supervisors are Professor Kerry Chamberlain and Dr Angela McNaught, also from the School of Psychology, Massey University.

#### Why is this research being done?

The purpose of this study is to explore and generate further understanding of the experiences of fathers during their child's cancer journey. Currently, there is a lack of research in this area, as most studies in the past have focused on the experiences of mothers. It is hoped that findings from this study may help to inform and improve the way in which health care professionals interact with and provide support to the fathers and families of children with cancer.

#### Who can take part in the study?

Eligible participants will be fathers of children who:

- (a) Have undergone a main course of treatment (involving chemotherapy or radiotherapy) for cancer within the last five years;
- (b) At any time during treatment were between the ages 4 and 12;
- (c) Are currently not an inpatient at Starship Children's Hospital;
- (d) Live in Auckland, New Zealand.

Participants will also need to be proficient in English.

The details about the project have been sent out to members of the Child Cancer Foundation. Word of mouth and networking amongst participants may also be used to recruit participants. It is estimated that 8-15 participants will be needed for the study.

#### What would participation in the study involve?

If you fulfill the requirements above and are willing to participate, you will be asked to take part in two interviews (approximately 30-60 minutes each). The interviews can take place in your home, workplace, or in Child Cancer Foundation buildings, at a time convenient for you. Your second follow-up interview will take place within a month of your initial interview. I would like to use quotes from your interview in my report, however no identifying details will be included. I would like you to bring objects of significance, such as photographs of your child during their treatment and their beads of courage, to each interview to talk about. I would like to photograph these objects, and to use these photographs in my

project, but I will seek your permission for the use of each individual photograph for this purpose at the close of the first interview. *Please note that if you agree to publication of any photographs of your child and/or family, you may not be anonymous in publications arising from this research.*

Recordings of your interviews, photos of objects of significance and any other data will be stored in a secure location and will only be able to be accessed by myself or my supervisors. No names will be linked to the stored data. Data will remain stored for five years and then disposed of in a safe manner. You will be gifted a \$40 petrol or grocery voucher as a token of appreciation for your time. In the event you would like to seek further support or discuss your experiences further, you will be directed towards available support services offered by CCF or local counseling services.

At the conclusion of the project, you will be mailed a summary of the results. The results may also be published as part of my thesis, at conferences and in scientific journals. Your name and any identifying details will not be used in any publications.

### **Your rights**

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to talk about any particular topics;
- ask for the recorder to be turned off at any time during the interview.
- withdraw from the study at any time (but if you withdraw more than two weeks after any interview, I will maintain your data in the dataset);
- provide information on the understanding that your name will not be used;
- be sent a summary of the project findings when it is concluded.

### **Ethics Approval**

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 13/006. If you have any concerns about the conduct of this research, please contact Dr Ralph Bathurst, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43404, email [humanethicsnorth@massey.ac.nz](mailto:humanethicsnorth@massey.ac.nz).

### **Project Contacts**

If you would like to participate, have any questions or would like further information at any time please contact either myself or my supervisors:

|  |  |  |
|--|--|--|
| Sarah Whitton  | Kerry Chamberlain  | Angela McNaught  |
| Doctorate of Clinical Psychology candidate                           | Professor  | Senior Lecturer and Clinical Psychologist                            |
| Massey University  | Massey University  | Massey University  |
| <a href="mailto:sarahmwhitton@gmail.com">sarahmwhitton@gmail.com</a> | <a href="mailto:K.Chamberlain@massey.ac.nz">K.Chamberlain@massey.ac.nz</a> | <a href="mailto:A.McNaught@massey.ac.nz">A.McNaught@massey.ac.nz</a> |
| 021 08160199   | (09) 414-0800, Ext 41226   | (09) 414-0800 Ext 41224  |

Thank you for taking the time to consider this invitation. I would greatly appreciate your collaboration in this study.

Yours sincerely,

*Sarah Cluley*



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## Appendix B

### Participant Consent Forms

#### Participant Consent Form

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to participate in this study under the conditions set out in the Information Sheet.

**Signature:**

**Date:**

**Full Name - printed**



### Participant Image Consent Form

Please note that if you consent to the use of photographs of your child and/or family, you may not be anonymous in publications arising from this research.

**Full Name - printed:**

**Date:**

Image number \_\_\_\_\_ Description \_\_\_\_\_

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I consent to this image being used in publications.

Name \_\_\_\_\_ Relationship \_\_\_\_\_ Signature \_\_\_\_\_

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I consent to this image being used in publications.

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Name \_\_\_\_\_ Relationship \_\_\_\_\_ Signature \_\_\_\_\_

Name \_\_\_\_\_ Relationship \_\_\_\_\_ Signature \_\_\_\_\_



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## Appendix C

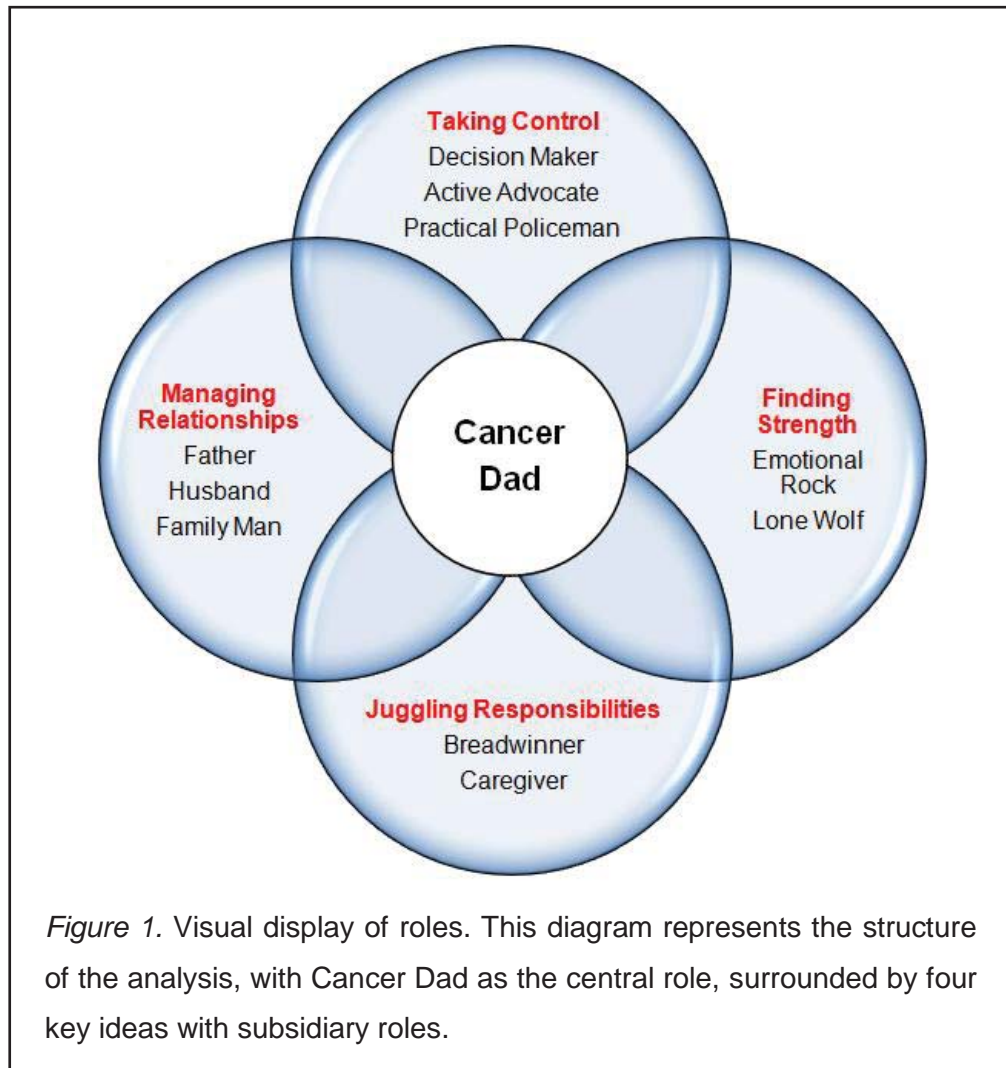
### Summary of Findings for Participants

Dear \_\_\_\_\_,

Thank you so much for your participation in the Massey University research project *Fathers of children with cancer: A narrative inquiry*, during 2013. I appreciate your willingness to share your story with me at that time, and I hope that you and your family are well. The research project is now in its final stages and I would like to share the findings and outcomes of the study with you. Without your help this study would not have been possible and I want to thank you again for your honesty and generosity in sharing your experiences of such a difficult time with me.

In total, twelve fathers from across Auckland participated in the study. The results were analysed using a particular method called narrative analysis, which focuses on the stories people tell about their experiences and the ways in which these are told. Roles were chosen as a way to capture how fathers constructed themselves performing different roles of fatherhood and as they responded to the challenges of their child's cancer diagnosis and treatment. Roles were seen to be fluid, interrelating, and could be transitional or ongoing. Some of these roles seemed thrust upon fathers, while other roles were chosen by them. Each role presented its own challenges of adjustment and identity. Some roles were not dissimilar from roles that might be identified in the accounts of fathers of healthy children, such as the role of Husband, or Breadwinner; however, the demands and challenges of these roles were heightened by cancer. Other roles were more time-limited and specific to the cancer experience, such as the Practical Policeman.

Analysis was focused around the central role of **Cancer Dad**, as following the initial diagnosis, fathers realised they had become a **Cancer Dad** and had to negotiate a period of shock and devastation as they grappled with the serious nature of their child's diagnosis and the uncertainty of their child's future. There were four main ideas which came out of an exploration of what it means to be a **Cancer Dad**: taking control, finding strength, juggling responsibilities, and managing relationships. Within each of these four ideas, there were several subsidiary roles that fathers experienced. See Figure 1 (next page) for a visual representation of the structure of the analysis, followed by a more in-depth explanation of each of the main ideas and subsidiary roles.



Firstly, Cancer Dads felt a need to **take control** of their child’s situation. In the role of **Decision Maker** fathers attempted to regain control by making decisions about their child’s situation. Similarly, when taking on the role of **Active Advocate**, fathers discovered the importance of being well-researched and assertive so they could stand up for their child’s best interests. Finally, fathers re-established a sense of control by taking charge of the practical areas of their child’s life and enforcing infection control and adherence to treatment in the role of **Practical Policeman**.

Secondly, Cancer Dads needed to **find strength** and the inner resources they needed to support themselves and their families through the trials of treatment. Fathers reported feeling pressured to take on the role of **Emotional Rock**, masking their own emotions in order to provide stability and support for their family. Fathers emphasised the importance of finding a safe or private way to vent their own emotions, rather than bottling them up and leaving them unresolved. Fathers also reported feeling disconnected and misunderstood, and some decided to move into the **Lone Wolf** role.



Although some fathers reported feeling reluctant to ask for or accept help from others, those that did accept help from friends and family found it very useful.

Thirdly, Cancer Dads needed to spend time **juggling their responsibilities**. Some fathers acting as **Breadwinners** found it difficult to meet work obligations and provide financially for their families during cancer treatment. Two fathers in particular faced significant challenges from their employers in their role as a Breadwinner and suggested the importance of seeking workplace advocacy. In the role of **Caregiver**, fathers often felt challenged by the expectation that caregiving was traditionally the mother's responsibility and at times felt undervalued and misunderstood by hospital professionals. Nevertheless, fathers valued the opportunity to be involved and spend time with their sick child as a part-time or primary Caregiver.

Finally, Cancer Dads felt they needed to **manage relationships** during the cancer journey. Due to the intensity of treatment, fathers reported that they spent a lot more time with their sick child which led to positive changes in that relationship. However, fathers also reported struggling to maintain boundaries for the sick child, and suggested the importance of being fair among siblings and putting effort into relationships with other children from the early stages, as otherwise they are likely to feel left out. During cancer treatment, stress, sleep deprivation, lack of quality time, and focus on the sick child put considerable strain on many **Husbands'** relationships with their wives. However, by supporting their wives through the difficult times, many Husbands found that their relationships were strengthened overall, and they had a greater appreciation for each other. Cancer Dads also reported prioritising their role as **Family Man** and spending more time with their children as a result of their cancer experience.

### **Ideas for Change**

Fathers also shared a number of ideas for change when they were talking about their experiences with the cancer process. These are summarised below:

- Health professionals and support workers could be encouraged to actively support fathers' involvement in their child's care. For example:
  - Inviting the father to attend the initial assessment and information session and letting him know that his input is welcomed and valuable
  - Creating a safe space in which fathers can ask questions and express their concerns may help to alleviate additional stresses and uncertainty.

- Fathers could be provided with additional opportunities for emotional support. These may include:
  - Connecting with other fathers of children with cancer, through groups and outings
  - Counseling support
  - Family outings with other families of children with cancer.
- Workplace advocacy services could be made available to fathers who need assistance to negotiate employment arrangements that will give fathers job security, while also allowing them the flexibility to meet personal and familial obligations.
- Budgeting and financial advice services could also be made available to fathers and families of children with cancer. Families should also be informed of any financial assistance they can access, such as parking permits, petrol vouchers, or benefits, at the beginning of treatment.

### **Outcomes of the Study**

In conclusion, this study has shown that fathers play a number of important roles following a child's diagnosis with cancer. It is hoped that the findings of this study will be able to be applied in appropriate settings in order to ensure fathers have the opportunity to play a key role within their child's care. The findings of the study have been passed on to Child Cancer Foundation (CCF), a key organisation in the care of children with cancer and their families. A brochure has also been created for fathers of children with cancer, with some ideas of what to expect on the road ahead, based on the stories shared by fathers who participated in this study, and will be disseminated via CCF. A copy of the brochure has been included in this letter for you to view.

If you would like to talk to me further about the findings or outcomes of the study, please contact me at [sarahmcluley@whiskersoft.com](mailto:sarahmcluley@whiskersoft.com) or on 02108160199.

Thank you again for your valuable contribution to this study.

Kind regards,

Sarah Cluley



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## Appendix D

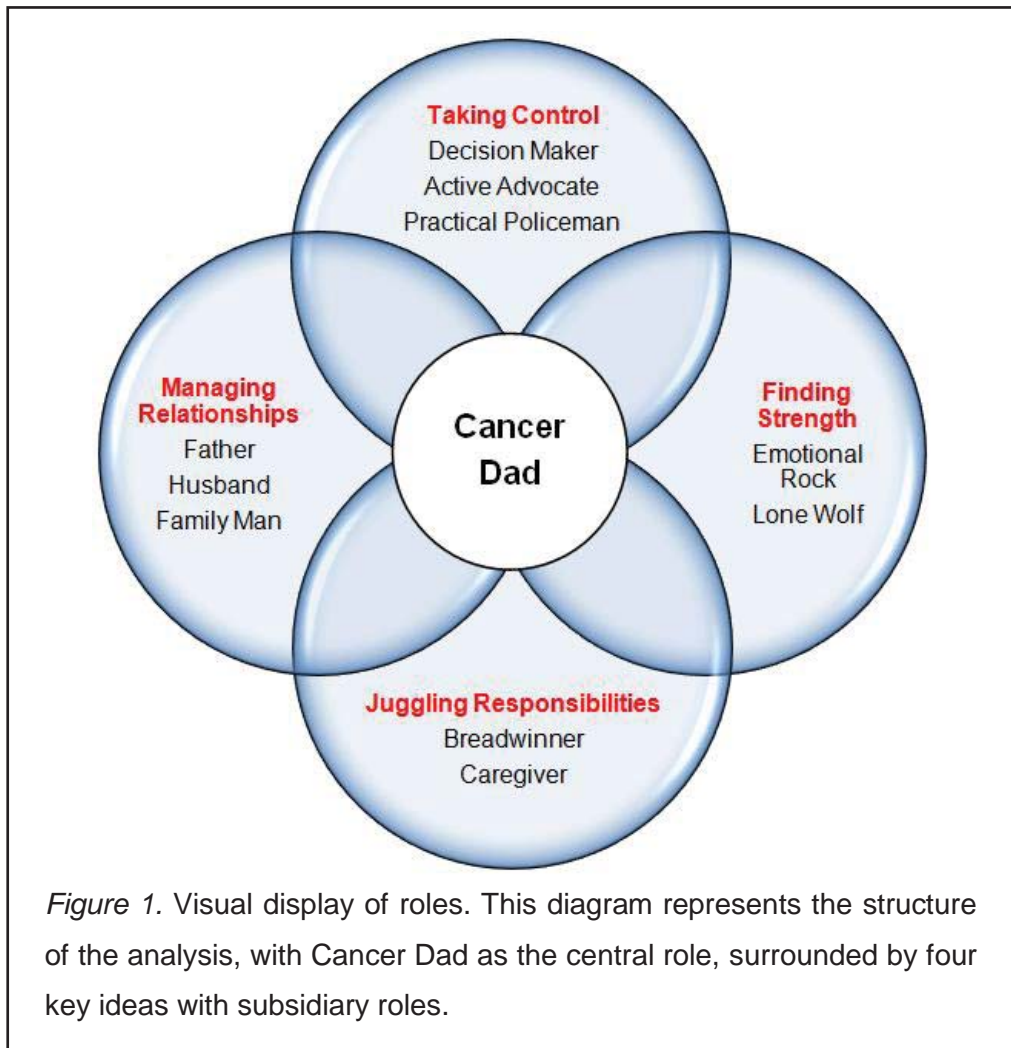
### Summary of Findings for CCF

Dear Maryanne Thomson and colleagues at Child Cancer Foundation,

Thank you so much for your willingness to help with recruitment for the Massey University research project, **Fathers of children with cancer: A narrative inquiry**. The research project is now in its final stages, and I would like to share the findings and outcomes of the study with you. Without your help, this study would not have been possible, and I want to thank you again for your honesty and generosity in assisting me by advertising my study in your newsletter.

In total, twelve fathers from across Auckland participated in the study. The results were analysed using a particular method called narrative analysis, which focuses on the stories people tell about their experiences and the ways in which these are told. Roles were chosen as a way to capture how fathers constructed themselves performing different roles of fatherhood and as they responded to the challenges of their child's cancer diagnosis and treatment. Roles were seen to be fluid, interrelating, and could be transitional or ongoing. Some of these roles seemed thrust upon fathers, while other roles were chosen by them. Each role presented its own challenges of adjustment and identity. Some roles were not dissimilar from roles that might be identified in the accounts of fathers of healthy children, such as the role of Husband, or Breadwinner; however, the demands and challenges of these roles were heightened by cancer. Other roles were more time-limited and specific to the cancer experience, such as the Practical Policeman.

Analysis was focused around the central role of **Cancer Dad**, as following the initial diagnosis, fathers realised they had become a **Cancer Dad** and had to negotiate a period of shock and devastation as they grappled with the serious nature of their child's diagnosis and the uncertainty of their child's future. There were four main ideas which came out of an exploration of what it means to be a Cancer Dad: taking control, finding strength, juggling responsibilities, and managing relationships. Within each of these four ideas, there were subsidiary roles that fathers experienced. See Figure 1 (next page) for a visual representation of the structure of the analysis, followed by a more in-depth explanation of each of the main ideas and subsidiary roles.



Firstly, Cancer Dads felt a need to **take control** of their child’s situation. In the role of **Decision Maker** fathers attempted to regain control by making decisions about their child’s situation. Similarly, when taking on the role of **Active Advocate**, fathers discovered the importance of being well-researched and assertive so they could stand up for their child’s best interests. Finally, fathers re-established a sense of control by taking charge of the practical areas of their child’s life and enforcing infection control and adherence to treatment in the role of **Practical Policeman**.

Secondly, Cancer Dads needed to **find strength** and the inner resources they needed to support themselves and their families through the trials of treatment. Fathers reported feeling pressured to take on the role of **Emotional Rock**, masking their own emotions in order to provide stability and support for their family. Fathers emphasised the importance of finding a safe or private way to vent their own emotions, rather than bottling them up and leaving them unresolved. Fathers also reported feeling disconnected and misunderstood, and some decided to move into the **Lone Wolf** role.

Although some fathers reported feeling reluctant to ask for or accept help from others, those that did accept help from friends and family found it very useful.

Thirdly, Cancer Dads needed to spend time **juggling their responsibilities**. Some fathers acting as **Breadwinners** found it difficult to meet work obligations and provide financially for their families during cancer treatment. Two fathers in particular faced significant challenges from their employers in their role as a Breadwinner and suggested the importance of seeking workplace advocacy. In the role of **Caregiver**, fathers often felt challenged by the expectation that caregiving was traditionally the mother's responsibility and at times felt undervalued and misunderstood by hospital professionals. Nevertheless, fathers valued the opportunity to be involved and spend time with their sick child as a part-time or primary Caregiver.

Finally, Cancer Dads felt they needed to **manage relationships** during the cancer journey. Due to the intensity of treatment, fathers reported that they spent a lot more time with their sick child which led to positive changes in that relationship. However, fathers also reported struggling to maintain boundaries for the sick child, and suggested the importance of being fair among siblings and putting effort into relationships with other children from the early stages, as otherwise they are likely to feel left out. During cancer treatment, stress, sleep deprivation, lack of quality time, and focus on the sick child put considerable strain on many **Husbands'** relationships with their wives. However, by supporting their wives through the difficult times, many Husbands found that their relationships were strengthened overall, and they had a greater appreciation for each other. Cancer Dads also reported prioritising their role as **Family Man** and spending more time with their children as a result of their cancer experience.

### **Feedback Specific to CCF**

Overall, fathers were very positive in their feedback specific to the services offered by CCF. In particular, a number of fathers commented that CCF had a good balance of offering services but allowing families to choose what they accessed:

They knew when to connect and when not to connect. *Jack*

They're good if you need them. I think if you want the support, they're there and if you wanna use these facilities they're great facilities, they're there. If you wanna talk to someone, you can talk to someone but if you don't, you don't and that's fine. We haven't felt the need to use them a lot. A lot of people do and that's great, they're here and that's the main thing. *Caleb*

Fathers who had CCF staff members involved with their child's treatment also expressed their appreciation of the services they provided:

We had our own minder come and hence where we got all these special beads – she's fantastic. Really nice and very helpful. Just come and sit with us in the early stages. Really good, can't sing their praises enough, very helpful. *Max*

And they were just good, they were explaining everything that was going on all the time, and you certainly go to know them, and they were very friendly. Yeah, definitely, yeah, hard, hard job for them to do, but they seem to enjoy it. *Mark*

Six fathers brought their child's Beads of Courage along to their interviews and spent some time explaining the significance of each colour bead and the special milestone beads. Fathers expressed support for the Beads of Courage programme and saw the beads as a powerful way of visually telling their child's story:

When we show these to people, it's very moving for them, cause they can actually see, it tells a story. *James*

Furthermore, a number of fathers mentioned the fathers' outings, family outings, and coffee groups which CCF runs. These were viewed as positive ways to connect with, support, and learn from other cancer parents:

Going to the CCF coffee groups, and talking to parents who, some of them have been out 9 years, but they still come back and answer questions, and this is how we did it back in our day, and you guys are different now. It's good to learn all those different things. *Ryan*

In addition to general suggestions for services which may be helpful for fathers, as described in the ideas for change section below, some specific feedback regarding CCF's services was given by two fathers:

There's no follow-up on treating the family unit, you know. And I think that's a big thing, a big, big thing. They may not have enough money to do that, but there is a lot of need, you know. And someone like CCF do a great job, but once again, it's only treating the kid. And they do some sibling stuff which is quite good ... I think there's a definite need in the actual family unit to be looked at, rather than just the clinical/medical disease covering of the whole thing. Because it's such a long period. And families are breaking down big time, you know. *Ryan*



I think CCF also need to be a little bit more realistic in maybe hosting things in an area. There's another family that we know of that's in the area. I don't know where they are. I don't know how their father feels, if he'd talk about it. I think they need to look in areas as well and offer services and get-togethers so father can all sit around and just talk about how things are going. *James*

### **Ideas for Change**

Fathers also shared a number of ideas for change (that were not specific to CCF) when they were talking about their experiences with the cancer process. Along with the ideas given by fathers above, these might be additional areas for CCF to explore to determine if they fit within their current model of care.

- Health professionals and support workers could be encouraged to actively support fathers' involvement in their child's care. For example:
  - Inviting the father to attend the initial assessment and information session and letting him know that his input is welcomed and valuable
  - Creating a safe space in which fathers can ask questions and express their concerns may help to alleviate additional stresses and uncertainty.
- Fathers could be provided with additional opportunities for emotional support. These may include:
  - Connecting with other fathers of children with cancer, through groups and outings
  - Counselling support
  - Family outings with other families of children with cancer.
- Workplace advocacy services could be made available to fathers who need assistance to negotiate employment arrangements that will give fathers job security, while also allowing them the flexibility to meet personal and familial obligations.
- Budgeting and financial advice services could also be made available to fathers and families of children with cancer. Families should also be informed of any financial assistance they can access, such as parking permits, petrol vouchers, or benefits, at the beginning of treatment.

## Conclusions

In conclusion, this study has shown that fathers play a number of important roles following a child's diagnosis with cancer. It is hoped that the findings of this study will be able to be applied in appropriate settings in order to ensure fathers have the opportunity to play a key role within their child's care. Thank you again for your contribution to recruitment of participants for this study. Please contact me if you have any further questions about the study or its results.

Kind regards,

Sarah Cluley

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## Appendix E

### Fathers of children with cancer: What to expect on the road ahead

#### Juggling Responsibilities

As a father, you may find it challenging to balance your work and caregiving obligations during your child's cancer treatment.

#### Managing Finances

Meeting work obligations and providing for your family during cancer treatment can be a tricky juggling act. Other fathers suggested talking with employers to negotiate flexible working arrangements during cancer treatment. Some fathers found it necessary to seek further advocacy when dealing with employers who did not understand their situation.

Fathers also advised seeking financial advice and utilizing budget planning services, particularly at the start of treatment, as most families experience reduced income during treatment.

#### Caregiving Responsibilities

Looking after your child can be demanding and you may experience sleep deprivation during their time in hospital. However, it is important to remember that you play an important role in supporting your child through treatment and recovery.

Other fathers sometimes felt the expectation that caregiving should be predominantly the mother's responsibility. However, all fathers reported that they valued the opportunity to spend time with their sick child and felt that they had played an important role in caring for their child.

Twelve fathers of children with cancer shared stories of their experiences as part of a doctoral research study. In doing so, their hope was to enable other fathers to better navigate their cancer journey. This brochure provides a summary of their responses.

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#### Early Stages

As a father learning for the first time about your child's cancer diagnosis, you can expect to experience strong emotions such as shock and disbelief. You may feel a sudden shift from being a 'normal' Dad to being a 'Cancer Dad' and may grapple with fears and uncertainties about your child's future. It is common to ask questions such as: why did it have to be my child diagnosed with cancer? What will this mean for my family in the next few days/weeks/months?

As a father, you may feel a sense of helplessness during the early stages of treatment. Other fathers in this situation found it helpful to take control of decision making, to become an active advocate for their child, and to take care of practical matters for the family.

#### Making Decisions

You may find that learning about your child's cancer and making decisions about their cancer treatment will help you to feel involved and useful.

When making decisions, other fathers emphasised that it is important to balance the expert knowledge you have of your own child, with the medical expertise of health professionals.

#### Managing Relationships

You may also face challenges in your family relationships during cancer treatment.

#### Father-Child Relationships

Spending a lot of time with your sick child may lead to positive changes in your relationship. However, other fathers reported that it is very important to set aside time to spend with your other children, so that they also feel loved and valued. It may be helpful to encourage your older children to take the opportunity to be involved in their sick sibling's care.

#### Partner Relationships

stress, sleep deprivation, lack of quality time, and a focus on your sick child, may strain the relationship you have with your partner. However, other fathers have suggested that supporting their partner and spending quality time together outside the hospital will be of benefit to maintaining a healthy relationship.

#### Importance of Family

Other fathers reported a renewed appreciation of their family, after journeying together through their child's cancer diagnosis and treatment. Many fathers decided to continue to prioritise spending time with their family.



#### Fathers of children with cancer

#### What to expect on the road ahead

based on the stories of twelve fathers who have been there

A summary of the findings of a narrative analysis by Sarah Cluley Massey University

#### Brochure Front

#### Being Active

After learning about your child's cancer, you may find it helpful to remain involved with your child's treatment and to become an advocate for them. You can help your child by being present during medical procedures, actively engaging with specialists when required, and making informed decisions about your child's care.

#### Being Practical

You may find it helpful to take a key role in practical areas such as family life and infection control, when caring for your child. Children tend to have a higher risk of infection during 'neutropenic' stages of chemotherapy (when the child's infection-fighting blood cell count is low). Other fathers found it helpful to keep an eye on their child's risk by monitoring the hygiene of family and visitors, thus minimising their family's contact with people who are sick.

You may find that at times you are asked to assist medical staff when your child is undergoing difficult medical procedures. Fathers suggested that though difficult, sometimes it is necessary to set aside your own emotions so that you can focus on what your child needs.



#### Brochure Inside

#### The Long Haul

Treatment for childhood cancer can be a lengthy and intensive process. Other fathers emphasised the value of emotional support and practical help in their own journeys. It is important that you find support in a way that works for you.

#### Managing Emotions

As a father, you may feel burdened by the expectation that you will be the rock that provides emotional stability for your family.

Treatment can be a very difficult time and you may find that you experience a range of emotions. Other fathers found it useful to hit punching bags, to let off steam at the gym, to cry alone in the car, to play video games, or to talk with friends in order to release their emotions. It is important that you find a safe way to express these emotions rather than bottling them up. Fathers who did not find a way to process their emotions found that it caught up with them later on.

#### Social Support

At times during your child's treatment you may feel isolated and disconnected, and that no-one understands what you are going through. It is important to find support – through family, friends, or by connecting with other parents of children with cancer. It is also important to ask for help when you need it. Although some fathers reported feeling reluctant to accept or to ask for help from others, those that did receive support found it very helpful.

## Appendix F

### Beads of courage: Narratives from fathers of children with cancer

*Sarah M. Cluley, Kerry Chamberlain, & Angela McNaught*

#### **Abstract**

A diagnosis of childhood cancer can be a life-changing event for both the child and their entire family. However, very few studies have focused specifically on the unique issues that fathers face or have explored fathers' perspectives on common challenges throughout a child's cancer treatment. The current study explored the experiences of fathers of children with cancer in Auckland, New Zealand, through an analysis of narratives relating to their child's beads of courage. The Beads of Courage programme is an international initiative which gives colourful beads to children with cancer as meaningful representations of their milestones, challenges, and courage during treatment.

Recruitment of participants was carried out with the help of a local charity called Child Cancer Foundation (CCF), who advertised the study in one of their newsletters. Data were collected as part of a larger study, in which fathers were invited to bring along objects of significance which could inform narratives about their experiences of their child's cancer. Six fathers chose to bring along

their child's beads of courage. The interviews were then transcribed and analysed using a narrative analytic framework. Analysis was focused around the ways in which the beads of courage were used as a narrative tool to provide insight into fathers' experiences of their children's cancer. Through the beads, fathers were found to construct narratives of order and chaos, create hope and encouragement from stories of suffering and hardship, and find personal meaning in the changes made and lessons learned through their cancer journey. The symbolic meaning of the beads identified by these fathers supports the importance of continuing the Beads of Courage programme in oncology centres and may help to inform support services through a greater awareness and acknowledgement of a father's personal journey alongside their child.

#### **Introduction**

A diagnosis of cancer during childhood can be life-threatening for a child and a traumatic experience for their entire family. Despite notable medical



advancements and an increase in childhood cancer survival rates (Greenlee, Murray, Bolden, & Wingo, 2000), cancer is still the second most common cause of childhood mortality (Ward, 2000). While each type of cancer has its own epidemiologic and biological characteristics, most childhood cancers have in common a lengthy, dangerous, and painful treatment process (Patterson, Holm, & Gurney, 2004).

Children may be required to undergo surgeries, chemotherapy, radiotherapy, or transplants as part of their individualised cancer treatments. Surgery usually involves an invasive procedure in which a tumour is removed, while radiation therapy involves the localised use of a high-energy radiation to eliminate cancer cells and keep them from reproducing (Cancer Society of New Zealand, 2009). Finally, chemotherapy is the use of anti-cancer drugs to kill cancer cells and stop them from dividing and multiplying (Cancer Society of New Zealand, 2012). These procedures can be painful or uncomfortable and are often associated with negative short- and long-term side effects, such as pain, hair loss, nausea, vomiting, anticipatory anxiety, and fatigue (Enskar, Carlsson, Golsater, Hamrin, & Kreuger, 1997; Hogan, 1997). The management of childhood cancer can mean hospitalisation for long periods of time, requiring a parent to remain alongside

their child. Furthermore, parents may need to coach their child through painful treatments, negotiate changes in the parent-child and sibling relationships, and manage role and occupational changes (McCubbin, Balling, Possin, Frierdich, & Byrne, 2002). The huge disruption to family life and strain on family emotional, financial, and interpersonal resources makes childhood cancer an especially challenging chronic illness for parents to deal with (Dockerty, Skegg, & Williams, 2003; Rocha-Garcia et al., 2003; von Essen, Sjoden, & Mattsson, 2004).

Fathers can play an important role in the family following a diagnosis of cancer. Neil-Urban and Jones (2002) argue that fathers can have a crucial influence on their child's emotional wellbeing and the stability of the family unit. Similarly, a recent review by Swallow, Macfayden, Santacroce, & Lambert (2011) concluded that fathers' contribution to their child's long-term health care was associated with a positive influence on overall family wellbeing, as well as on fathers', mothers' and children's psychosocial wellbeing. While it appears that fathers can have a significant role in family adjustment following a diagnosis of cancer, very few studies have focused specifically on the unique issues fathers face, or have explored fathers' perspectives on common challenges throughout their child's cancer treatment. Furthermore,

fathers have historically been underrepresented in pediatric oncology research (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005) and have demonstrated low participation rates in studies looking at both parents (Liaschenko & Underwood, 2001). In part, this may be because mothers are more likely to be primary caregivers of their sick children (Zebrack, Chesler, Orbuch, & Parry, 2002) and thus may be perceived as more knowledgeable informants for research (Chesler & Parry, 2001; Phares et al., 2005).

Having a child with cancer can often lead to an increase in childcare demands for parents. Mothers often become primary caregivers of the ill child while fathers may be faced with the challenge of juggling more intensive involvement with the care of their child and the fulfilment of financial and other responsibilities (Quittner et al., 1998). In New Zealand, the context for this study, there has been an increase in childcare responsibilities undertaken by fathers, as reflected by an increasing number of single father households (Statistics New Zealand, 2006) and families where the father is the primary caregiver (Statistics New Zealand, 2013). This change has also been paralleled in the wider Western world – previously fathers took on a predominantly supportive role, while more recent research has documented the active involvement of the father in caring

for their children (Bonner, Hardy, Willard, & Hutchinson, 2007; Brody & Simmons, 2007; Jones, Pelletier, Decker, Barczyk, & Dungan, 2010). As greater responsibility regarding childcare has been taken on by fathers (Wolff, Pak, Meeske, Worden, & Katz, 2010), more research is needed to investigate fathers' changing role in the context of a child with cancer.

The small number of studies which have focused on the father's perspective of their child's cancer have suggested that fathers cope with emotional stress by remaining optimistic, taking on a protector role for their family, seeking information about their child's cancer, staying calm and tightly controlling their emotions, and distracting themselves with work and other activities (Brody & Simmons, 2007; Jones et al., 2010; Reay, Bignold, Ball, & Cribb, 1998; Yeh, 2004). Some fathers have also reported positive personal transformation resulting from their experiences of a child with cancer (Chesler & Parry, 2001). In research focusing on a father's perception of their role following a child's diagnosis, a number of fathers expressed the belief that their role was to be strong, suppress their emotions, and provide support for other family members during their child's treatment (Brody & Simmons, 2007; Chesler & Parry, 2001).

The current study aimed to gain insights into how fathers understand and account for their experiences of being



fathers of a child who has been diagnosed and treated for cancer. We examined their narratives surrounding their child's beads of courage. We focused on the beads of courage because these beads were very often produced in the interviews and in turn, produced enhanced accounts of their experiences.

### **The Beads of Courage programme**

As part of the Beads of Courage programme, colourful beads are given to children as meaningful representations of their milestones, challenges, and courage during cancer treatment (Beads of Courage Inc., 2013a). A bead guide dictates the colour and shape of the bead a child will receive for a particular treatment, procedure, or milestone. For special accomplishments or milestones, the child is allowed to choose a bead from a special selection of more elaborate beads. Similarly, for an act of courage, or a difficult procedure, such as a bone marrow or stem cell transplant, the child may choose from another collection of glass beads.

The Beads of Courage programme aims to decrease cancer-related distress, help children find meaning in their cancer, provide them with a tool to illustrate their cancer story, and to assist them to find a renewed sense of self while on their cancer journey (Beads of Courage Inc., 2013a). Since its development by

oncology nurse Jean Baruch in 2002, the programme has been implemented by more than 150 hospitals throughout the United States, Canada, United Kingdom, Japan, and New Zealand (Beads of Courage Inc., 2013b). While the collection of beads can be a special part of the cancer journey for a child with cancer, it can be equally meaningful for their parents (Baruch, 2010; Penkman, Scott-Lane, & Pelletier, 2006).

To date, only one study (Baruch, 2010) has investigated the perspectives of parents on the Beads of Courage programme. The study used focus groups and open-ended surveys to investigate the significance of the beads for parents of children with cancer. Baruch's (2010) survey results suggested that most parents strongly believed that the programme was worthwhile and found it valuable, while content analysis of interviews suggested that parents found the beads programme to be a source of encouragement, a helpful record of progress, a long-term reminder of accomplishments during treatment, and a recognition of their child's courage and accomplishment. In light of the significance of the programme suggested by this study, and the lack of father-focused research in oncology, the current study aimed to explore fathers' experiences of their children's cancer, through narratives of their children's beads of courage.

## Method

### Narrative analysis

A narrative has a number of distinctive features: it is an account of events that have occurred, or are expected to occur, and it is coherent, causal, and structured with a certain plot or shape (Denzin, 1989; Murray, 2003). A narrative is a story which constructs a series of past events to give them meaning for the narrator and his or her listener (Denzin, 1989). Narratives are often regarded as the primary means through which human experience and identity are constructed, described, and understood (Bruner, 1990; Linde, 1993; Maitlis, 2012). As such, narratives represent a social construction of the narrator's world, and a way of establishing connections between thoughts, feelings, actions and events (Gergen, 1999).

The use of narrative methodologies to explore illness experiences (and inform caring) is particularly relevant as it focuses on the participants' specific, individualised stories, capturing the complex and contextual nature of their experiences (McCance, McKenna, & Boore, 2001). Personal narratives can provide a unique window into the meanings a person has constructed around their experiences, and the ways they conceptualise what has happened to them (Parker, 2005; Riessman, 2001). A narrative analytical approach assumes that a storyteller has strategically created

their narrative and it is up to the researcher to uncover and analyse the story as a reconstruction of the narrator's lived experience (Riessman, 2004). Consequently, the development of an overarching, integrative narrative from a number of participants' narratives may involve a consideration of how different elements shape their stories: the use of structure, themes, and character by the narrator, as well as the broader influence of cultural context.

Narrative analysis is an appropriate methodology for the investigation of the experiences of fathers of children with cancer because it encourages the researcher to look deeply into not only the content of narratives a participant chooses to share, but also how they construct these narratives, and what this says about their view of themselves and the world. The use of narrative analysis in the current study may provide considerable insights into the meaning-making process for fathers of children with cancer, and greater understandings about the cultural context within which their narratives were formed.

The use of objects of significance within interviews can enhance and encourage narrative talk, add intricacy and depth to accounts of experience, prompt reflexivity by participants, and add to insights and interpretation by researchers (Collier & Collier, 1986; Morgan & Pritchard, 2005; Pink, 2004;

Sheridan & Chamberlain, 2011). In the context of this study, where fathers were asked to share their experiences of their child's cancer, it was hoped that the inclusion of the beads of courage would provide a reconnection to the past and provide a multidimensional, multisensory interviewing experience for both participants and researcher. The use of the beads of courage to inform talk may bring greater clarity to vivid memories from a difficult time, and allow fathers to share, remember, and reflect upon their own journey alongside their child.

### **Data collection**

Data were collected as part of a larger study, in which fathers were invited to bring along objects of significance which could inform narratives about their experiences of their child's cancer. Six fathers chose to bring along their child's beads of courage, confirming how significant these can be. It is their data which is included in this paper. The use of objects in this paper was driven by the idea that objects such as beads of courage could provide a symbolic reference point that had the potential to stimulate and deepen narratives. Pink (2004) contends that the addition of objects to interviews may engage other senses and add further dimensions to a participant's representation and expression of their lived experience. Similarly, Sheridan and Chamberlain

(2011) argue that the use of objects can enhance narrative interviews by providing proof of the past, increasing narrative depth, and producing change in narratives. It was hoped that bringing along objects would inform talk by bringing greater clarity to vivid memories from a difficult time, and enhancing the way fathers to share, remember, and reflect upon their own journey alongside their child's.

Fathers were invited to participate in the study through a newsletter sent out by the Child Cancer Foundation to Auckland-based families of children with cancer. Each participant was the biological parent of a child (2-12 years of age) who had undergone a course of treatment involving chemotherapy or radiotherapy for cancer within the last five years, and who was not a hospital inpatient at the time of interviewing. The six participants ranged from 40 to 54 years of age at the time of the interview, and identified their ethnicity as New Zealand European (n=4), English (n=1), and Cook Island Maori (n=1). Ethical approval was obtained from the University Human Ethics Committee. Fathers also gave their consent for the use of photographs taken of beads of courage in publications.

### **Interviewing and analytic process**

Two unstructured interviews were conducted with each participant. This

allowed participants and the researcher additional time for reflection and recollection of memories between interviews. The interviews were digitally recorded, transcribed, and analysed by the first author. Interviews were carried out at participants' homes, workplaces, or the university, between July and November 2013, and were between 15 and 150 minutes. The second interview was usually significantly shorter than the first. Following each interview, and again after transcription, analytic notes were taken, recording initial thoughts, reflections, and observations by the primary researcher. At the start of each interview, fathers presented objects that they had brought along because they related in a significant way to their child's cancer journey. Fathers were asked for permission to photograph items, and often engaged in an active way by arranging items in a specific fashion for photographing. In order to protect the anonymity of fathers and their children, the photographs of the beads of courage were later digitally altered to change the child's name. Participants and their children were given pseudonyms and care was taken to omit any additional identifying information from the analysis and discussion.

Initially, each individual transcript and its corresponding beads of courage photograph, were placed together and examined for narrative ideas. This pairing

allowed a comparison of thematic and structural ideas in each transcript and its corresponding beads of courage photograph. Mind-mapping and a comparison table were then used to explore the relationships between concepts and themes emerging across participants. Similarities and differences were identified and used to form cohesive narratives. Analytic work was carried out by the first author and then discussed with the other authors after the initial planning stage and again after each draft was completed.

## **Analysis and Discussion**

### **The beads of courage as a narrative tool**

The way in which fathers introduced their child's beads of courage seemed to communicate the value placed on the beads as a visual narrative tool – a means of telling their child's story. Frank (1995) argues the importance of the narrative voice for those who are ill – they “need to become storytellers in order to recover the voices that illness and its treatment often take away” (p. xii). While this may be true, we argue that the storytelling can also be a powerful way for fathers of children with cancer to recover their own voices around their own struggles and experiences of their children's suffering, and that beads of

courage can act as a vehicle for these narratives.

One father, Robert, whose daughter was diagnosed with leukemia, described the beads as “a snapshot of what we went through”. This conveys a sense of the beads as a visual representation of not only his child’s story, but of his own and his family’s stories – what “we” went through. There is also a sense that what one can infer from the number and colour of the beads is only a “snapshot”, or a brief glimpse, into the deeper narratives represented by the huge range of beads collected. Two other fathers also alluded to the sheer enormity of what they and their child had been through by drawing attention to the number of beads and their meaning:

His beads would actually go around this room. Huge. That’s how many chemical interventions he’s had over the years ... we strung them all up and they snapped, it was that heavy. We needed a massive piece of fishing wire to get them on there.

*Jack*

And that’s the very first one there with her name on. Yellow ones are night stays, green are neutropenic ... black ones are what they call pokes, i.e. injections, and the white ones are chemo. These are ... psychologists’ [sessions] and all that sort of thing, and these are challenge ones. These are what

they call a bone marrow aspirate, where they actually take the bone marrow out. This one there ... is a lumbar puncture, and every one of these egg type ones, you see them all through here, that’s every hundred. She’s got 900 beads so far. Well, just over 900. She has another string, which is almost finished, but not finished that we can hang it up yet, so we’re just over 900, and we started in Easter last year [i.e. 18 months ago]. *Max*

Each father made a point of explaining the significance of the colour of each bead and of the more special challenge beads as parts of their story. The way in which participants chose to present the beads and their construction of the arrangement of the beads also served to establish a framework for their stories. The creation of an ordered account was indicated by two fathers who spent some time arranging their child’s beads of courage in a specific pattern for the researcher’s photograph, and drew attention to the way in which the beads of courage were ordered to mirror the progression of treatment and procedures given. As the beads are given out separately as part of the programme, it is the families who actively impose structure and meaning on the beads by stringing them together in a particular order or shape. The first father, James, laid out the beads in a spiral pattern (see Figure 1),



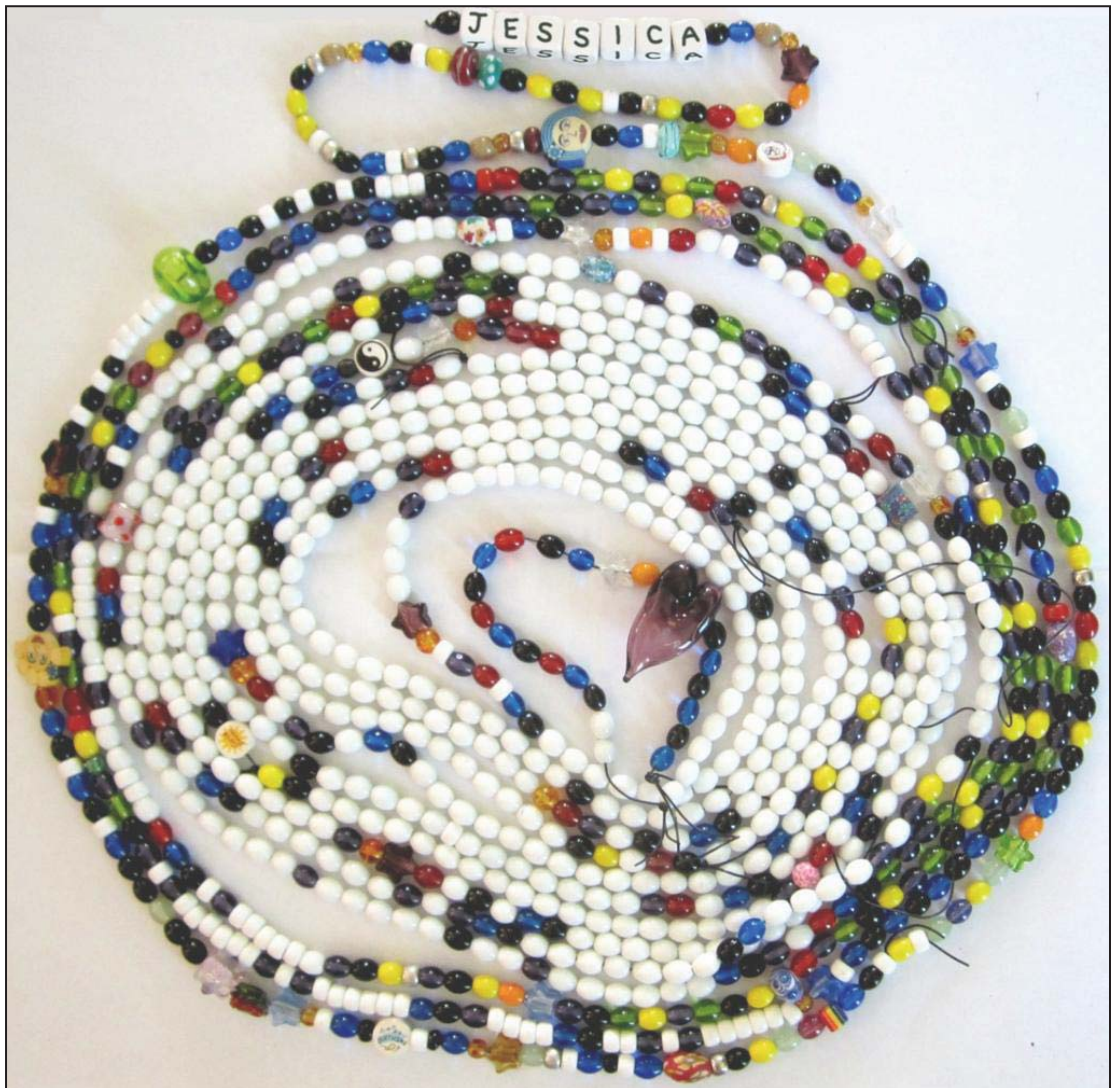
with his daughter's name at the top, and the purple heart symbolising the end of treatment in the centre of the spiral. He explained:

The whole treatment thing just goes. The way it branches and twists and turns, it's quite bizarre at times. Everybody's experience is different. Not everybody's results are the same.

Here, James makes sense of his

daughter's journey by structuring it as a unique spiral of colours, with a defined shape, beginning and end. The spiral pattern is constructed as being symbolic of the ever-changing nature - the "twists" and "turns" of treatment – and may be perceived as an attempt to create order in hindsight, despite the uncertainty of outcome which characterised the course of his daughter's treatment.

We tell the story from start to finish



*Figure 1.* A photograph showing James' daughter Jessica's beads of courage laid out in a spiral fashion.



and all the bits in between are all there... it's a chronological story, we felt it was the best way to remember things.

In this way, James positions the beads as a storytelling device which marks the passage of time and provides a tool for remembrance and communication. As a family, they have carefully created a story from their pile of beads by stringing them together in chronological order to illustrate and preserve memories of the course of treatment. The idea of using objects in research to communicate and provide visual proof of one's story has also been discussed by Sheridan and Chamberlain (2011). They argue that objects such as photographs can be used to bear witness to an experience, mark the passage of time, and act as a visual insight to those who have not experienced the past. While it can be argued that the beads of courage performed all three of these functions in the current study, it is clear that the desire to use the beads to provide proof of one's story and to communicate what one's child has "been through" was not restricted to the researcher-participant relationship. Fathers communicated that the beads were an important tool for illustrating their story to others in their daily lives, outside the scope of the research study:

When we show these to people, it's very moving for them, 'cos they can actually see, it tells a story.

This suggests that the beads did not take on their narrative qualities solely for this study, but that fathers actively used the beads as a storytelling device to aid communication with other people and to facilitate understanding about their child's and their own cancer journey. Another father, Max also constructed a narrative of order through the way he presented his daughter's beads. The beads were strung into a number of loops. Max carefully laid out each loop, starting with his daughter's name and beads from the beginning of treatment, and then adding each subsequent loop, in an arrow-like formation (see Figure 2). At the time of interviewing, Max's daughter, Hillary was still completing her three-year treatment for leukemia as an outpatient, and so while his daughter's story did not yet have an end, it seemed as though each new layer of treatment represented forward progression towards the goal of completion. A sense of order was also present in the arrangement of the beads:

My wife put them in perfect order, so that way it really tells a story, instead of, wow, that's a pile of white ones, and a pile of black ones, and a pile of green ones.



Figure 2. A photograph showing Max's daughter Hillary's beads of courage laid out in an arrow-like formation.

The idea of the beads as a storytelling device and a means of constructing a sense of order and meaning from a time of uncertainty and chaos was clearly apparent from the way in which these two fathers introduced their child's beads of courage. This illustrates the argument made by Radley and Taylor (1990) that people make sense *with* objects, not *of* them. Chronological arrangement of beads by families as they string them together, and the careful

presentations of the beads in a particular shape by these two fathers, are congruent with this idea as meanings were not created by the objects themselves; rather the objects were a means of making sense of a larger narrative. Other participants also used the beads as a device to communicate a larger story, but often introduced narratives of chaos, rather than order, as reflected in their placement of the beads. For example, Jack's presentation of his son Matthew's



Figure 3. A photograph showing Jack's son Matthew's beads of courage presented in a more chaotic arrangement.

beads takes on a more chaotic appearance (see Figure 3). His story of his son's leukemia journey is not a tidy, neat, ordered narrative with a conclusion.

While his son finished treatment several years ago, it is clear that the prospect of relapse or long-term side effects continue to haunt Jack:

Cancer is always hanging over you, the spectre that looms. It's made me appreciate him more really. The fact that he could be gone. You know, even now, we still get scared. Just, it's like this spectre that always looms over you. Never goes really. You know, just before Christmas we got told he may have a heart defect

as a function of the medications he'd had. Oh my God, here we go again. So if the cancer doesn't kill you, the medication might. So as long as your kid's in remission, you're happy. When you start getting the telltale signs, you know parents of kids who relapse, you know they've relapsed. You know roughly, you can see it. You know, that spectre that's arriving on your doorstep, it's there, it's waiting. I think as he gets older, he realises where he's come from, what he's done, the significance of it all. Don't think we've actually thought about it



yet. We still think we're in it. The spectre. The spectre that looms.

Jack strings together a number of short phrases, which spill out quickly, building up a sense of emotional tension and emphasising the lack of control he feels. He gives a sense that his mind is racing and will not be put to rest while the "spectre" of cancer continues to "loom" over his child. The journey is not clearly over, not for his child, nor for him as an ever-watchful father. For this father, there is no resolution, no sense of order or finality, for his son's future is still uncertain. This story resembles the chaos narrative described by Frank (1995), a storyline featuring vulnerability, powerlessness, and a sense of hopelessness. However, Jack's story is not entirely a story of wreckage, as there are threads of hope and a sense that although future challenges may emerge, the main battle of surviving cancer has been won.

### **Narratives of suffering and hope**

The beads of courage also became a way through which fathers could express narratives of suffering and challenge in cancer. In particular, fathers used special challenge beads to tell the story of medical or emotional challenges their child faced, and to express their pride in their child's resilience and courage. Narratives of loss, suffering, and

hope were shared through the stories embedded in the special challenge beads chosen by each child. In particular, most fathers were quick to point out one or two beads with the illustration of a face, which signified hair loss. For some participants, the loss of hair was much more than just a physical side effect as it marked a dramatic change in their child's appearance and served as a public marker of their disease:

That was always hard to take him out for a walk, people looking. He was like this little bald-headed extra-terrestrial running around.

*Jack*

And when she had no hair and she was wearing a bandana and what have you and she would walk down the street looking like that, and ... complete strangers, some would know and they'd give us a smile and a nod, but that's human nature, I know that. Others would just, oh, interesting thing in the window. It was very obvious. We got to a point we would just laugh about it. What else can you do? It's either that or you cry. You can't do that. You can see how she's changed from there til you see her now. *Max*

These fathers struggled with the physical transformation of their child and the subsequent reaction of strangers. Hair has historically been associated with beauty (Holm, Patterson, & Gurney,

2003b), and the loss of hair has been seen to denote a loss of individuality and attractiveness (Björk, Wiebe, & Hallström, 2009; Tobin & Begley, 2008). In the context of cancer, their child's loss of hair was a powerful visual reminder for fathers of the loss of their child's health, previous appearance, and carefree years of their childhood as a result of treatment. Woodgate (2006) also argues that family narratives about a child with cancer's loss of hair are representative of a deeper realisation of the loss of a beautiful, healthy child. In addition to the realisation of loss, these narratives provide a direct challenge to each father's identity as a protector of their child. Not only must fathers grapple with their inability to protect their child from the pain from cancer and medical treatments, but they must try to protect their child's self-esteem from the stares and reactions of strangers. There is a sense of grief and wanting to cry at the loss of the child's hair and a normal childhood, but instead the father must protect his child and transform the situation into one to laugh at – "what else can you do? It's either that or you cry. You can't do that."

Other challenge beads were also used to tell stories of suffering and hard times during treatment. While the stories focused on particular hardships, they were also bound up with fathers' recognition of their child's bravery and courage in the past and hope that their

child would also overcome challenges in the future.

The bigger ones are courage, brave. They all mean different things ... he had surgery and they pulled out all his baby teeth. Must have had about seven they had to pull out. *Luke*

Special medical challenges ... all these big fancy ones. This one was one of her first bad side effects you could say. It's a bit of a funny one in some ways. She got, with Vincristine, one of the chemotherapy drugs, she got terribly constipated and she was going, everything seemed to be right, is what we thought, but in actual fact what was happening is we found out from the x-ray is we have what, seven and a half metres of intestine? She was completely full. Complete. The whole lot. And on the x-ray it showed that. So when Hillary saw that challenge bead she picked it, obviously. We were in hospital for a whole week, seven days thereabouts for it, because they couldn't do it from the back end, they had to go from the top end. And that's just one of many challenges that she's had. They're all here somewhere. This is really what we hold to ourselves. *Max*

Those are the kind of memories when they've got milestones...

those are the things we hang on to.

*Robert*

Each challenge bead serves as a trigger for a story of what the child has overcome, and it is through these stories that we hear of the child's courage, bravery, and resilience through the eyes of their father. Woodgate and Degner (2005) reported a similar narrative idea expressed by mothers of children with cancer who found great personal strength in their child's spirit and the depth of courage they displayed during treatment. They argued that the cancer experience was made more tolerable for mothers when their child was able to maintain spirit in the face of adversity (Clarke & Fletcher, 2005). Similarly, in future crises, fathers stated that they can hold on to the memories of what their child has accomplished already and hope that they will pull through again. It may be that fathers reframe narratives of hardship as "milestones" to hang on to in order to feel hopeful about the future and to make their current experiences of cancer more tolerable. Furthermore, memories of their child's strength and resilience during painful aspects of treatment can evoke pride in fathers and become a source of personal strength as they undergo their own challenges and hardships as a father of a child with cancer:

These needles came out and she was just sitting on the bed and the nurses came either side and put the

spray on, a special cold spray that numbs, and just goes boom, and very stoic our daughter. She just sat there and just went, "You're going too slow and you're doing it right." Cos the one nurse that was going slow she could feel it, but the one that went fast, was good. And they just were blown away. They said, "Can we take a photo of this? We've never had a child do that yet!" *Max*

I was quite proud of the way she handled her treatments. Her injections consisted of a needle in each leg as close to the bone as they could get. She didn't even flinch for that and was quite proud of her for that. I think the nurses were probably more shocked themselves. *James*

These narratives express the pride felt by fathers at their daughters' brave reactions when given injections, as symbolised by black beads. Both fathers make a point of describing the nursing staff's response in a way which emphasises how special and courageous their daughters were. This pride may then encourage fathers to look at their own reactions to adversity and to find strength and inspiration in the way their child is coping with their treatments. Especially for fathers whose children are still undergoing cancer treatments, the strings of beads already collected may mark the



enormity of what had already been overcome and provide motivation to continue the fight alongside their child. One father shared his hope not to acquire any more yellow beads for overnight hospital stays during his daughter's outpatient treatments:

The last long haul we had was over Christmas, from Boxing Day. Actually we were in the hospital before Christmas, we were home for Christmas Day and then back in again ... it was three weeks, and that's the last long run we've done in hospital. And between the four of us, we've said, "That's it, no more yellow beads," and so far, touch wood, we haven't. We came close three weeks ago. Max

For Max, the beads of courage became a symbol not only of hardships overcome in the past, but a source of motivation and hope for the remainder of his daughter's treatments. Through the beads, he was able to unite with his wife and two daughters in the hope of preventing any further long stays in hospital – "no more yellow beads." Through times of suffering and challenges signified by beads of courage, fathers can construct narratives of hope, inspiration, and motivation that bring meaning to the hardships endured and encouragement for the future.

## **Narratives of change**

The beads of courage are a powerful visual representation of all that a child and their family have gone through. In this way, the beads of courage can be used as a reflective tool, a lasting reminder of challenges overcome and the journey of cancer. Robert explained that they kept the beads in a prominent place in their home, such as "hanging on the door, so it's a daily reminder ... for the kids as well". Max similarly expressed a desire to put the beads in a public place and to "frame them all, so it's her name but written out in the beads. So she can have it forever". Underlying the importance of keeping the beads in a prominent position in the house is the perceived significance of the beads:

We often get the beads out, makes you think of where you've been and what you've done. It's a lot, it's a lot. I think as he gets older, he realises where he has come from, what he's done, the significance of it all. *Jack*

The beads are also upheld as a reflection of a change in identity – Jack's son is a survivor of a four-year battle with leukemia. He has persevered through multiple chemotherapy treatments, steroids, infections, hair loss and other side effects. He has overcome many challenges. Likewise, the beads are a reminder to the father to reflect on his own change in identity – who is he as a father in light of what has happened?

Where has he journeyed with his child, what have they overcome together? Lee and Owens (2002) argue that changes in social structures and more egalitarian expectations for couples mean that a man's experiences at work have decreased in importance and experiences within his family have become increasingly important for his identity. This argument is particularly salient in the case of a cancer crisis, where the redirection of time and energy towards the sick child and family can challenge a man's identity as a father, shift his priorities, and promote changes in his life. Fathers in the current study reported becoming more aware of their roles as a protector and provider for their family, and becoming a person who was more appreciative of family and less likely to worry about the small issues as a result of their child's cancer journey.

It's made me appreciate him more really, the fact he could be gone.  
*Jack*

As I've said we've always wanted to do things as a family, so we were close anyway. But it's just made us a bit closer, I suppose. *Max*

I try not to sweat the small stuff too much and this even more so has changed that now where I find myself, "It doesn't even matter," and move on. *Dan*

I think, for me, the way I look at it is that we've been through heaps; I don't think he needs to go through more. I'm protective, I think. *Luke*

Guess you've got to do the best for the family. So work very hard but I spend much more time now at home. You know, spend more time with the children ... as a father you've got to provide better. *Caleb*

Crisis can bring change in a person's identity and priorities in life, and each of these fathers suggested positive changes in themselves as a result of their child's cancer. The beads served as a reminder of their roles as a protector and a provider for their family, and of the changes they had observed in themselves. By framing their narratives as a positive change or lesson they have learned, these fathers are constructing meaning out of their experiences. While the event of the cancer itself was outside of their control, they can control the creation of meaning-laden stories about their experiences. In this way, the beads became a reminder of lessons learned and personal changes made and a way to bring order and meaning to their experiences. Constructing illness as a motivating force for change is characteristic of quest narratives, as described by Frank (1995). However, while Frank suggests that quest narratives create accounts of transient illness and focus on resolution, the

possibility of relapse and long-term treatment effects may add ambiguity to these fathers' narratives and prevent their narratives from reaching resolution.

### **Conclusions**

The beads of courage have been used as a narrative tool to provide insight into fathers' experiences of their children's cancer. Through the beads, fathers have constructed narratives of order out of memories of a chaotic time, have created hope and encouragement from stories of suffering and hardship, and have found personal meaning in the changes made and lessons learned through their child's and their own cancer journey.

The beads of courage are more than simple trinkets collected by a cancer child as recognition for undergoing medical procedures; they hold a wealth of symbolic meaning, memories, and identity for the fathers of children with cancer. They are a lasting reminder of narratives of hardships overcome, hope, resilience, personal changes, and lessons learned. The symbolic meaning of the beads identified by these fathers supports the importance of continuing the Beads of Courage programme in oncology centres. Deeper knowledge of the challenges, milestones, and growth experienced by fathers in the midst of adversity may help to inform support services through a greater awareness and acknowledgement

of a father's personal journey alongside their child.

This study also has broader implications for the field of clinical psychology. Qualitative methods can be particularly effective for psychological research questions, such as those of the current study, which involve exploration and analysis of subjective or constructed meaning (Camic, Rhodes, & Yardley, 2003) as they provide rich, idiosyncratic, and practical insights into human experience. Findings from this study can also be used to bring about a greater understanding of fathers' experiences of their child's cancer, which in turn can be used to inform psychological interventions for this population. The effectiveness of using the beads of courage as a narrative tool to uncover meaning for fathers of children with cancer in the current study furthermore suggests that perhaps more thought might be given to the use of objects and metaphors within more traditional cognitive-behavioural therapies, particularly for client groups that find it difficult to express themselves, or are unsure of where to start.

Research suggests that metaphors and images can be powerful tools for use during therapeutic work with a client (Stott, Mansell, Salkovskis, Lavender, & Cartwright-Hatton, 2010). Cognitive-behavioural therapists can incorporate images, metaphors, and analogies to deepen an understanding of the client's

presenting issues during assessments, when challenging unhelpful styles of thinking, and when addressing maintaining behaviours (Blenkiron, 2005). The use of metaphors and stories can increase rapport, provide an alternative perspective for clients, enhance clarity of meaning, and reinforce motivation to pursue change. Metaphors can also be effectively used within Acceptance Commitment Therapy, narrative therapies, child therapies, trauma therapy, and other treatment modalities (Burns, 2007).

The use of imagery has also been suggested to be effective within a Compassion Focused Therapy framework, where clients create and explore their image of their ideal of compassion in order to undermine shame, self-blaming and self-condemnatory safety behaviours (Lee, 2005). Similarly, Competitive Memory Training (COMET) uses imagery to enhance self-esteem by making images of positive and worthwhile characteristics better retrievable from long-term memory (Korrelboom, van der Weele, Gjaltema, & Hoogstraten, 2009). COMET training has been found to be effective in depressed (Korrelboom, Maarsingh, & Huijbrechts, 2012), panic-disordered (Korrelboom, Peeters, Blom, & Huijbrechts, 2014), eating-disordered (Korrelboom, de Jong, Huijbrechts, & Daansen, 2009), older adult (Ekkers et al., 2011), and schizophrenia-spectrum

populations (Gaag, Oosterhout, Daalman, Sommer, & Korrelboom, 2012).

In summary, this study has provided an important contribution to the psychological literature, as well as facilitating a personal journey of learning and development. Through conducting this research, I learned a great deal about qualitative methods, interviewing techniques, the power of metaphors and stories, and the experiences of fathers of children with cancer in New Zealand. The breadth and depth of fathers' experiences reminded me of the importance of being client-led in my therapeutic interactions and highlighted the significance and effectiveness of using metaphors. As a result of this study, I would like to make a greater effort to incorporate narratives and metaphors into my own clinical practice as a means of better understanding clients' experiences and the meaning they attach to those experiences. Furthermore, this study has challenged me to seek to better understand groups which may feel overlooked or less understood, such as fathers of children with cancer, and to adapt therapeutic interventions within clinical practice accordingly.

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**STATEMENT OF CONTRIBUTION  
TO DOCTORAL THESIS CONTAINING PUBLICATIONS**

(To appear at the end of each thesis chapter/section/appendix submitted as an article/paper or collected as an appendix at the end of the thesis)

We, the candidate and the candidate's Principal Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

**Name of Candidate:** Sarah Cluley

**Name/Title of Principal Supervisor:** Prof. Kerry Chamberlain

**Name of Published Research Output and full reference:**

Cluley, S. M., Chamberlain, K., & McNaught, A. (2015). Beads of Courage: Narratives from fathers of children with cancer.

**In which Chapter is the Published Work:** Appendix F

Please indicate either:

- The percentage of the Published Work that was contributed by the candidate:  
and / or

- Describe the contribution that the candidate has made to the Published Work:

Candidate has written complete drafts of the paper. Supervisors have contributed through feedback.

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