Benefit Finding in Parental Cancer: Types and Predictors of Benefits and their Influence on Depression and Well-being

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B Psych (Hons)

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Certificate of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person, nor material which to a substantial extent has been accepted for the award of any other degree or diploma at Charles Sturt University or any other educational institution, except where due acknowledgement is made in the thesis. Any contribution made to the research by colleagues with whom I have worked at Charles Sturt University or elsewhere during my candidature is fully acknowledged.

I agree that this thesis be accessible for the purpose of study and research in accordance with the normal conditions established by the Executive Director, Library Services or nominee, for the care, loan and reproduction of theses.

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Publications

The following article derived from this thesis has been accepted for publication:


Statement of contribution: The candidate, Janelle Levesque, was the primary author of the article. She wrote the original draft of the article, handled all elements of submission, and responded to journal feedback and requested revisions. The candidate was responsible for the development of the key idea behind the study, the methodology and data analysis. Darryl Maybery acted as PhD supervisor during this time, offering guidance and technical support as required.

Co-author certification of inclusion of article in thesis:
I, Darryl Maybery, give permission for the article listed above to be included as an appendix in the thesis titled Benefit Finding in Parental Cancer: Types and Predictors of Benefits and their Influence on Depression and Well-being.

Name: Associate Professor Darryl Maybery

Signed: .................................................................

Date: ...18th August 2011..................
Abstract

Cancer is a disease that affects the entire family, therefore consideration must be given to the psychological needs of each member. Several studies have explored the impact of parental cancer, most commonly with a focus on psychopathology and/or young children. The possibility of positive psychological growth in the adult offspring of cancer patients has been largely overlooked, a void that is filled by this thesis.

The concept of benefit finding fits within the theoretical field of posttraumatic growth. Such theories argue that traumatic events challenge the individual’s core psychological schemas, and prompt the individual to engage in cognitive processes to create positive changes. This thesis explores the suggestion that, for many people, parental cancer meets the criterion of a traumatic stressor, and therefore benefit finding can occur.

Operationalised within the theoretical position of posttraumatic growth, this thesis reports on two studies to determine if benefits occur as part of the parental cancer experience. The thesis determines and quantifies the types of benefits that arise, and compares them to the benefits reported in the literature by cancer patients and spouses. The thesis then highlights the relationships between benefit finding and psychological outcomes.

Eleven adult children of parents who had cancer were interviewed in the first qualitative study. Interpretative phenomenological analysis revealed seven themes, four relating to benefit finding, and three relating to negative elements of the experience. All participants were able to identify positive outcomes arising from their parent’s cancer. Positive changes in the areas of improved relationships with their sick parent, valuing family, altered life priorities and personal development were reported. The negative themes reflected the emotional impact of cancer, grief and loss, and involvement in caregiving.

Preparation for Study Two revealed no measures available to adequately assess the experience of parental cancer for adult children. As a result, a
Parental Cancer Questionnaire (PCQ) was developed to reflect both positive and negative experiences of parental cancer for adult offspring. A quantitative survey of 311 adults, whose parents had cancer, then examined the participants’ experience, and their psychological outcomes. Initial analyses determined the component structure and reliability of the newly developed PCQ, finding it to be a reliable, three-factor scale, measuring parental cancer benefits, emotional experiences, and caregiver strain.

Study Two confirmed that benefit finding occurs in adults whose parents have cancer, particularly in the area of family. The predictors of benefit finding were emotional experiences, carer satisfactions, and outcome of parental cancer. Benefit finding was a significant negative predictor of depression; however, it had no relationship to anxiety, stress, or well-being.

The findings of the thesis are then illustrated in light of the theoretical and empirical literature, and are discussed in terms of the new knowledge generated from these studies. The thesis also highlights key clinical considerations regarding how best to incorporate the concept of benefit finding into clinical interventions. The thesis also developed the PCQ, a scale with potentially wide clinical and research utility that is specific to the cancer experience. The development of the PCQ addresses a clear gap in the assessment literature. Limitations of the thesis are also outlined. Overall, the findings are important, because they make an initial step to develop the scant knowledge regarding the adult experience of parental cancer.
Chapter 1: Thesis Overview

1.1. Introduction

Cancer is a major health issue in Australia, accounting for approximately 29% of all deaths each year, including a significant health burden (i.e., health care, absenteeism for work, disability) with over 100,000 new cases diagnosed each year (Australian Institute of Health and Welfare [AIHW], 2010). Improvements in both detection and treatment have also meant that the five-year survival rate is increasing, with the prevalence of cancer in Australian society having grown to 1 in 31 Australians living with the disease (AIHW, 2010).

With better prognosis and more patients reaching the five-year survival milestone, more families are living with the disease and its consequences for longer periods of time. Consequently, there is growing recognition that cancer not only affects the patient, but their entire family (Rait & Lederberg, 1990; Veach, Nicholas, & Barton, 2002). Despite the recognition that cancer affects family members, there has been a paucity of research conducted on the psychological outcomes among the adult children¹ of cancer patients. Furthermore, the adult child research that has been conducted has tended to focus on negative outcomes, such as depression, anxiety, poor psychosocial adjustment, and posttraumatic stress disorder (e.g., Bowman, Rose, & Deimling, 2006; Boyer et al., 2002; Kissane, Bloch, Burns, McKenzies, & Postering, 1994; Lindberg & Wellisch, 2004). While there is great value in such work, it provides very little insight into the parental cancer experience for the majority of adults, who do not report psychological disturbance, and thus our view of the experience is incomplete.

In parallel, the notion of posttraumatic growth has blossomed in the last 15 – 20 years, with the positive psychology movement embracing the concept of finding something good from negative experiences (Janoff-Bulman, 1989; Tedeschi & Calhoun, 1995; Taylor, 1983). The narrow focus on psychopathology as an outcome of parental cancer has ignored the

¹ The term adult child has been used throughout this thesis to refer to any individual over the age of 18 years, when their parent was diagnosed with cancer.
growing evidence that positive psychological outcomes (i.e., benefit finding) can arise from cancer in patients and spouses. For example, a large number of studies have shown that cancer patients report positive changes arising from their illness, such as improved interpersonal relationships, self-development, changes in outlook, and a reprioritisation of life goals (e.g., Bellizzi & Blank, 2006; Schulz & Mohamed, 2004; Thornton, 2002; Weiss, 2002). There is also increasing evidence that spouses report similar types and level of change (e.g., Dorval et al., 2005; Manne et al., 2004; Thornton & Perez, 2006; Weiss, 2002).

The concept of benefit finding is positioned within posttraumatic growth theory, with such theories arguing that traumatic events challenge the individual’s core psychological beliefs, bringing forth a re-examination of basic assumptions (Janoff-Bulman, 1989; Tedeschi & Calhoun, 1995). Through various cognitive processes, individuals alter their core schemas, and from this may emerge the acknowledgement of beneficial changes that have arisen from their traumatic experience. Another school of thought is that posttraumatic growth represents a cognitive illusion that assists the individual to cope with the crisis created by traumatic events (Taylor, 1983; Taylor & Updegraff, 2000). Current theorising suggests that both forms of growth may be possible, and may serve different functions at different stages of adjustment to the traumatic stressor (Maercker & Zoellner, 2004; Zoellner & Maercker, 2006). This thesis argues that parental cancer can be conceptualised as a traumatic event, based on the definitions of trauma proposed by growth theories. The experience of the adult child of cancer patients is an important area that remains largely unexplored.

To date, the adult child cohort has been largely overlooked in the area of perceived benefit finding. This is a considerable void, especially if one considers the estimation that over one million adult Australians\(^2\) will be

\(^2\) This estimation is based on the following information: The cancer prevalence rate is estimated at 650 000 cases (AIHW, 2010) and the average fertility rate in Australia in 2009 was 1.9 babies per woman (Australian Bureau of Statistics [ABS], 2010a), therefore 1.9 X 650 000 = 1 235 000 children with a parent with cancer. The fertility rate used in this estimation is lower than previous years, for example the baby boomer generation average fertility rate was 3.5 babies per women (ABS, 2010a). The above estimate is therefore considered conservative. It is acknowledged that a very small proportion of the cancer prevalence rate will reflect childhood cancer cases (approximately 600 cases per year
affected by a parent with cancer. Furthermore, as most cancers occur later in life and the survival rate increases, most patients’ children will be in adulthood, so there is a considerable number of people for whom this is a particularly relevant topic. This thesis presents the findings of two studies conducted to investigate the possibility of benefit finding in adults whose parents have cancer.

1.2. Thesis Aims

The overall aim of the thesis was to determine whether adults perceive benefits from having a parent with cancer. Study One was a qualitative study that sought to determine if benefit finding was perceived by adult children as an outcome of parental cancer and, if so, what type of benefits were reported. Once this aim was confirmed, it was possible to compare and contrast the types of benefits reported with the patient and spouse literature, while examining the data from the theoretical perspective of posttraumatic growth.

Study Two was a quantitative extension of Study One, aiming to confirm that benefit finding was perceived to be a possible outcome of parental cancer, and examining the types of benefits. This study investigated the concept of benefit finding, firstly looking at variables that might be predictive of benefit finding, and then examining the role that benefit finding plays in the psychological outcomes arising among adults whose parents have cancer.

1.3. Overview of the Thesis Structure

This thesis comprises 10 chapters which examine the related literature, outline the methodological features, report and discuss the findings of both studies, and then draw together the main implications and conclusions from the research.

Chapter 1 – Thesis Overview, briefly introduces the topic area of the thesis, providing a brief justification for the study, while also outlining the

[Cancer Council Queensland, 2010] and families with children aged 0-17 years; therefore to accommodate such cases the conservative fertility rate was used.
Chapter 2 – Psychological Impact and Outcomes of Parental Cancer, provides an overview of the study context, including a description of the incidence of cancer in Australia, the significance of the disease for the adult child, and presents the argument that parental cancer should be considered a traumatic stressor. The chapter reviews the literature on adult children in response to parental cancer, finding that such literature focuses on psychopathology. A review of the literature examining benefit finding and posttraumatic growth in cancer is then undertaken, with a brief summary of patient and spousal studies to establish that benefit finding can occur in response to cancer. Finally, the chapter reviews the scant literature on positive psychological outcomes arising from parental cancer, relying heavily on qualitative works that have examined the overall experience of parental cancer.

Chapter 3 – Theories of Posttraumatic Growth, reviews the theoretical literature on posttraumatic growth, focusing on two theoretical schools of thought that view positive changes as either an outcome or an illusion. Several current debates within the literature are noted and discussed, with concerns raised regarding conceptual ambiguity, measurement of the concept, and how growth relates to psychological outcomes. This chapter concludes with a clear statement of the aims of Study One.

Chapter 4 – Study One Methodology, outlines the methodology and theoretical framework which underpin the first study. This chapter also details the method utilised, participant characteristics, recruitment procedures and participation requirements. This chapter and several related appendices provide a summary of the processes involved in data analysis, and serve as a measure of the methodological rigour employed in the study.

Chapter 5 – Study One Results and Discussion, presents the findings of the qualitative study, providing evidence of the benefit finding
phenomenon within the adult child cohort. This chapter also highlights several negative aspects of the parental cancer experience, reminding the reader that benefit finding emerges within a context of struggle. The key themes are related to existing research, and an examination of the data in relation to key theoretical concepts is conducted. The methodological limitations of the study are raised, and areas of future research are identified. This chapter was developed into a paper titled Parental cancer: Catalyst for positive change and growth, which was accepted for publication in the international peer-reviewed journal *Qualitative Health Research* (see Appendix A).

Chapter 6 – Study Two Rationale and Methodology, begins with the justification for Study Two, and a clear statement of the research aims and hypotheses for the quantitative study. It then outlines the method employed in the completion of Study Two, detailing the characteristics of the sample and outlining the measures used. The chapter also details the development of the Parental Cancer Questionnaire (PCQ), a scale developed specifically for use in Study Two. The procedural details and recruitment strategy are also included.

Chapter 7 – Study Two Principal Components Analysis of the Parental Cancer Questionnaire, presents the results of the analysis conducted to determine the PCQ’s component structure. Issues relating to the component structure are discussed, and a final scale structure is proposed. An analysis of the scale’s reliability, and evidence relating to the PCQ’s validity, are also presented.

Chapter 8 - Study Two Results Relating to Research Aims and Hypothesis Testing, examines the results of the quantitative study, confirming that benefit finding does occur in response to parental cancer. The chapter examines the types of benefits reported, and identifies variables that are predictive of benefit finding. An interesting finding regarding the possibility of the outcome of parental cancer acting as a moderator in the prediction of benefit finding was explored, and the results are reported. Finally, an analysis to investigate the potential value of benefit finding in
the prediction of the psychological outcomes of depression, anxiety, stress, and well-being was conducted and presented.

Chapter 9 – Discussion of Study Two Findings, examines the results of Study Two in light of the existing empirical and theoretical literature. The limitations of the study are noted, and avenues for future research proposed. The author tentatively proposes the clinical application of the findings, noting the concerns regarding the suitability of using growth-related interventions in clinical practice.

Chapter 10 – Summary of Findings, and Implications for Future Research and Clinical Practice, draws together the key findings of Study One and Study Two. The chapter highlights the knowledge contributed by this thesis, while emphasising avenues for future research and potential clinical implications of the findings. The degree to which the aims of the studies were met is also discussed.
Chapter 2: Psychological Impact and Outcomes of Parental Cancer

This chapter provides a context for the thesis by examining the cancer statistics in Australia, and considering the life-span developmental challenges that adult children may face when they encounter the experience of parental cancer. A review of the literature is then conducted examining the psychological impact and outcomes of having a parent diagnosed with cancer. The majority of studies examine pathological psychological outcomes with little reference to the possibility of deriving psychological benefits from the experience. In response to this assertion, the final sections of the chapter examine the concept of benefit finding in the context of cancer for patients, spouses, and adult children.

2.1 Cancer in Australia

Cancer is a term used to describe more than 100 diseases that are characterised by excessive, abnormal cellular growth due to mutations in the cell’s genetic material (Australian Institute of Health and Welfare [AIHW], 2010). This abnormal cellular division can result in the development of a lump or mass, and may also create cells that invade and destroy the surrounding tissue (Veach et al., 2002). Tumours, which remain non-invasive and limited to the site of their development, are usually benign and non-life threatening, whilst cancers, which destroy tissue and spread, or metastasise, carry a greater risk of mortality (AIHW, 2010).

The causes of cancer are not fully understood, although much is known about risk factors that increase an individual’s likelihood of developing cancer. The AIHW (2010) report three main categories of risk factors: biomedical, lifestyle, and environmental. Biomedical factors refer to an individual’s genetic susceptibility and hormonal factors among females. Numerous lifestyle factors have been identified and include smoking, alcohol consumption, diet and weight issues, physical inactivity, and chronic infections. Environmental factors include excessive exposure to sunlight, radiation, and other environmental pollutants, such as chemicals and asbestos. While many of these risk factors can be avoided, it is noted
that the simple presence of a risk factor does not guarantee that the individual will develop cancer; rather it increases the likelihood that they will develop the disease, at some stage in their life cycle (AIHW, 2010).

The incidence of cancer in Australia remains high, with over 108,000 new cases of the disease being recorded in 2007, and the risk of being diagnosed with cancer by age 85 being 1 in 2 for males and 1 in 3 for females (AIHW, 2010). Cancer was recorded as the second most common cause of death in Australia in 2007, accounting for approximately 29% of all deaths (AIHW 2010). The most commonly reported cancers in Australia are prostate, bowel, breast, melanoma, and lung cancers, and together these five cancer types accounted for 61% of new cancer cases diagnosed in 2007 (AIHW, 2010). The mean age at diagnosis is around 67 years for males and 64 years for females. The vast majority of cancer cases occur in people aged over 50, and the overall incidence of cancer increases with age, with the highest incidence of cancer reported in individuals aged 80 and over (AIHW, 2010). For example, the risk of colon cancer jumps from one in 36 for people aged 75 to one in 18 for people aged 85 (AIHW, 2010).

There is also evidence that the rate of cancer is on the increase in Australia. According to AIHW statistics, in 1982 the number of new cases of cancer diagnosed was approximately 47,000, while in 2007 it was 108,000. Taking into consideration population growth and the ageing population, adjusted statistics suggest that there has been a 27% increase in the number of cancer cases diagnosed in Australia over the period from 1982 – 2007, suggesting that the incidence of cancer is on the rise (AIHW, 2010). This represents a significant challenge to the community in terms of cost (e.g., health care, absenteeism from employment) as well as a threat to the physical and psychological well-being of both the patient and their family (Australian Bureau of Statistics [ABS], 2010b).

While the incidence of cancer may be increasing, the mortality rate is actually decreasing. In the period from 1998-2008, the standardised death rate from cancer decreased for both men (from 262 to 232 deaths per 100,000 men) and women (from 156 to 144 deaths per 100,000 women) (ABS,
2010b). Consequently, there is a growing proportion of people diagnosed with cancer who are surviving the disease, with approximately 63% of cancer patients reaching five year survival status (Tracey, Chen, Baker, Bishop, & Jelfs, 2006). This increased survival rate has led to an increased prevalence of the disease in Australian society. In 2004, it was estimated that there were over 650,000 living individuals who had been diagnosed with cancer (approximately 1 in 31 Australians), with almost half of all cases (over 297,000) being diagnosed within the period from 1999-2004 (AIHW, 2008, 2010). Consequently, there are a growing number of patients and their families living with the disease, its consequences, and the fear of recurrence for longer periods of time. As outlined earlier, considering that there are approximately one million adult Australians with parents who have cancer, it is crucial that research is undertaken to gain an insight into the experience and understanding of the impact of parental cancer, particularly from a positive point of view, as there are potentially important ramifications for a large group in society.

2.1.1 Parental cancer and its relevance to the adult child.

Over the last 15-20 years, there has been growing recognition that cancer is a disease that affects the entire family, and that the family’s role is no longer just to support patients, but they may be in need of support themselves (Veach et al., 2002). In recognition of this paradigm shift, Rait and Lederberg (1990) termed the phrase “second-order patients” (p. 585) to acknowledge that family members are intimately affected by cancer in a loved one, and that they have their own pattern of psychological needs. Some of the issues, which are particularly pertinent to family members, include fear associated with loss and personal health risk, emotional isolation, coping tasks that support the patient, assisting in treatment decisions, care-related strain, and uncertainty about the future (Junge, 2005; Veach et al., 2002). It has also been found that the experience of cancer has a long-term effect on family members, especially in regard to the fear that another family member may be diagnosed with the disease (Ryst, 2004).

The diagnosis of parental cancer effects the functioning of the family system, not just in terms of shattering emotional equilibrium, but also in
terms of roles, communication, and systems of interaction. Ryst (2004) suggests that, to deal with the day to day aspects of living, families must change daily routines, roles need to be altered within the family group to pick up activities that the sick parent is no longer able to perform and, as such, the social structure of the family may shift. Some family members may find an increase in status and responsibility as they become the caregiver, which in turn changes their self-concept (Ryst, 2004). The impact of such changes may be influenced by the developmental stage of the family members. For example, the diagnosis of parental cancer may be more expected in middle aged adult children, as parental illness and death are anticipated events at this age for adult children (Moss & Moss, 1989). Furthermore, parental illness may be less disruptive to personal development during middle age, as this stage is characterised by career stability and effort into important aspects of life, such as family (Holland & Rowland, 1990). In contrast, parental cancer during young adulthood may be particularly disruptive, as it may interfere with the major developmental goals of this period as the adult child attempts to separate from the family home and to establish life and career goals, intimate relationships and their own family (Puterman & Cadell, 2008).

The majority of research conducted on the impact of cancer on family members has tended to focus on the spouse, and then the children and adolescents of the cancer patient (i.e., those aged 18 and below, who are primarily still living at home). This is understandable, as such family members will have virtually daily contact with the cancer patient, and therefore the potential impact of the disease is increased. To a much lesser extent, research has been conducted into the impact of parental cancer on adult children (i.e., those aged 18 and over at time of diagnosis), and existing studies have tended to combine adult child data with spousal data (into groups termed family members), so that no clear conclusions can be drawn. This is a significant void in the literature, as most cancers typically occur in people aged over 60, whose children are likely to be adults. Considering that, in the majority of cancer cases, the patient’s children will be adults, it is important to increase the knowledge of how cancer affects this cohort. Whilst it may be argued that most adult children live
independently from their parents, it should not be concluded that the impact of parental cancer is minimised, simply because the dependent child-parent relationship is no longer present. Rather, there is some suggestion that adult children feel a great degree of filial responsibility, often more than their parents expect (Logan & Spitze, 1996). It can also be argued that observing one’s parent experience physical and emotional suffering, and potentially preparing for bereavement, is highly traumatic for adult children. Furthermore, parental cancer may give rise to issues related to the child’s own genetic risk of the disease, leading to confronting issues relating to their own mortality (Mosher & Danoff-Burg, 2005).

Despite these arguments, the current understanding of how parental cancer impacts on adult children is incomplete, and this therefore presents challenges to organisations that endeavour to formulate suitable support services. The following section examines the research evidence regarding the psychological outcomes of parental cancer in the adult child cohort.

2.2 Psychological Outcomes of Parental Cancer in Adulthood

The majority of the existing research into adult children of cancer patients is commonly negative, examining the presence of psychological disturbance arising from parental cancer. Overall, there is a strong suggestion that parental cancer is a significant stressor for adults, with many reporting clinical symptoms as a result of their experience. It is also important to note that, in some studies, the emotional disturbance is higher for the adult child than for the patient or spouse (e.g., Bowman et al., 2006; Edwards & Clarke, 2004; Kissane et al., 1994), reinforcing the position that they are second order patients with their own combination of psychological needs.

A study by Kissane et al. (1994) examined depression and anger in 102 families (patient, spouses and offspring aged 12 and above). Among this sample, 28% of children met the diagnostic criteria for depression, and they reported similar levels of anxiety to their sick parent. An important finding in this study was that children reported levels of anger and hostility which were significantly higher than patients. Kissane et al. (1994) suggest
several explanations for this elevated anger, including the presence of anticipatory grief, the perception of inadequate communication and conflict within the family, and the role changes and subsequent role strain that arises from balancing new parental care needs with their procreative family and career.

The finding of heightened levels of emotional reaction is echoed in the research of several others. For example, Harrison, Haddad, and Maguire (1995) found that 48% of relatives (combined spouses and children) scored above the usual cut-off score of the General Health Questionnaire, suggesting high levels of distress and significant psychological morbidity. Furthermore, the relatives reported significantly greater levels of cancer-related concerns compared to cancer patients (the median concern scores were 16 and 4 for relatives and patients respectively).

Other studies have examined not only the presence of psychological distress, but also factors that may contribute to it. Edwards and Clarke (2004) reported that 20.8% of relatives were at risk of depression compared to 12.8% of patients. Furthermore, 60.2% of relatives were at risk of poor psychosocial outcomes compared with 47.9% of patients. This study also examined aspects of family functioning, and concluded that families with open expression of feelings and effective problem-solving reported lower levels of depression, while direct communication of information within the family reduced anxiety (Edwards & Clarke, 2004). This supports the contention by Veach and Nicholas (1998) that informing and including the family can address the feelings of hopelessness and powerlessness that may contribute to poor psychological outcomes. In a study examining how illness variables influence psychological distress, Compas et al. (1994) found that the perceived seriousness and perceived stressfulness of the situation increased depression and anxiety in young adult children, whilst the time since diagnosis tended to decrease depression and anxiety.

There is also some suggestion that adult children may report long-term negative impacts from the cancer experience. For example, the study by Bowman et al. (2006) of family members of long-term cancer survivors
found that relatives appraised the situation as more stressful than the cancer patients. Bowman et al. (2006) suggest that this finding may be due to feelings of helplessness in family members during treatment, and communication difficulties surrounding the topic of cancer which, in turn, colours their overall evaluations of the experience. Similarly, a study by Ell, Nishimoto, Mantell, and Hamovitch (1988) examined psychological functioning in family members during the 12 months post-diagnosis. They found that family members did not demonstrate psychological adaptation, but rather that there was a significant decline in the mental health status of family members within the first 12 months of diagnosis. Their findings have important implications, as they observed that individuals with poorer psychological functioning at the time of diagnosis were more likely to report a decline, compared to individuals with better psychological functioning at diagnosis, suggesting that at-risk family members could potentially be identified early in the cancer journey, and appropriate support could be provided to minimise psychological decline. Furthermore, the family members’ psychological functioning was unrelated to the patient’s psychological functioning (Ell et al., 1988), suggesting that it is possible for a patient to cope well with their diagnosis, but for their family members to experience high psychological disturbance.

To examine the psychological outcome of family carers of cancer patients, Pitceathly and Maguire (2003) conducted a literature review and drew some important conclusions. They found that the rate of psychological morbidity (i.e., major depressive disorder, anxiety, or adjustment disorder) amongst carers ranged from 20-30% for self-report studies and 10-33% for studies using trained interviewers, and that the rate of morbidity increased during the palliative stage to a range of 30-50% of carers (Pitceathly & Maguire, 2003). Current estimates of mental health disorders in Australia suggest that approximately 18% of adults experience psychological disorders, the most common being anxiety disorders (14%) and mood disorders (6%) (ABS, 2006, 2009). Considering the national statistics in the light of the findings of Pitceathly and Maguire, it seems that involvement in caring for a parent with cancer may increase the risk of developing a psychological disorder, especially during the palliative stage where the rate
of psychological morbidity more than doubles national estimates. Pitceathly and Maguire also concluded that carers were at greater risk of psychological morbidity if they were female, had a history of psychological disturbance, lacked appropriate social support, and experienced relationship difficulties with the patient. In the conclusion of the review, Pitceathly and Maguire argued that there is still much to be learned about how interpersonal and intrapersonal factors influence psychological morbidity in cancer caring, but that existing retrospective, correlational research has limited the understanding of the experience.

One problem with all of the studies reviewed above is that the samples they have utilised are not exclusively the adult children of cancer patients. Frequently, the data from adult children is combined with spousal data, with no differentiation made based on the relationship to the cancer patient. It is also typical that, if such information is published at all, the proportion of adult children in the sample is significantly smaller than that of spouses. For example, the sample in the study by Ell et al. (1988) was 70% spouses, 11% adult children and 10% were significant friends. In samples where only children have been included, there are issues regarding the ages of the children studied. Specifically, Kissane et al. (1994) researched individuals aged 12 and up, while Compas et al. (1994) limited their age range from 6 - 30 years. While Compas et al. considered age-related differences by performing analyses on different age groups, the break-up of the child sample into age categories resulted in a small sample of adult children (\(n = 34\)), which may have subsequently reduced the power of the study and restricted the analysis that could be performed. Furthermore, by setting a maximum age limit for participation, the study by Compas et al. excludes the age range in which parental cancer typically occurs. It is therefore suggested that the data collected to date from younger participants may not be representative of older adult children, especially if one considers the vast differences between the developmental stage and age-related challenges that the child may be experiencing alongside their parent’s cancer. Consequently, while the existing research seems to suggest that psychological morbidity is a common outcome from the experience of
parental cancer, caution must be taken when interpreting such findings due to sampling issues.

The exception to this style of methodology seems to be studies that examine the first degree relatives of cancer patients. First degree relatives are those who share approximately 50% of their genetic material, such as one’s parents, siblings, and children (National Human Genome Research Institute, n.d.). Most of this research has focused on the daughters of breast cancer patients (e.g., Baider, Ever-Hadani, & De-Nour, 1999; Erblich, Bovbjerg, & Valdimarsdottir, 2000; Wellisch & Lindberg, 2001). Typically, these cohorts have consisted of adults, however, once again the results of these studies may not be representative of the general population of adults whose parents have cancer, due to the differing levels of genetic risk associated with some types of cancer (e.g., breast and colon cancer have stronger familial incidence patterns compared to lung cancer and leukaemia; Cancer Council South Australia, 2008). It is possible that the types of distress and psychological outcomes of parental cancer may vary depending on the level of perceived personal risk associated with genetic heritability. Despite this limitation, the studies reviewed in the following paragraphs do provide some insight into the range of emotional reactions and issues that face the children of some cancer patients.

The general conclusion from many studies examining psychological outcomes among daughters, whose mothers have breast cancer, is that daughters do experience a heightened level of distress. For example, in a qualitative study of 50 caregiving daughters, Raveis and Pretter (2005) found that daughters experienced a range of long-lasting emotional reactions, such as panic, fear and sadness, and concluded that the life and death issues, which caregiving daughters face, parallels the existential dilemma that patients experience. Furthermore, the recognition of an increased personal risk of cancer either shattered the notion of immunity from cancer, or confirmed a familial vulnerability to the disease (i.e., in cases where a grandmother or aunt had already had breast cancer), creating a situation where the daughter had to strive to provide support to their
mother, whilst simultaneously processing the implications of the disease for themselves (Raveis & Pretter, 2005).

Quantitative studies support the conclusion of increased psychological distress in daughters of breast cancer patients. Baider et al. (1999) found in their sample of 230 healthy first degree relatives of breast cancer patients ($n = 196$ daughters), more than 50% met the diagnostic level of psychopathology according to the Global Severity Index of the Brief Symptom Inventory (Derogatis, 1993). Furthermore, Baider et al. found that women, who reported the highest levels of psychological distress, also tended to report high levels of intrusion as measured by the Impact of Event Scale (Horowitz, Wilner, & Alvarez, 1979). Similarly, Valdimarsdottir et al. (1995) found that first degree relatives reported significantly higher levels of non-specific distress, avoidance and intrusive thoughts in relation to breast cancer, in comparison to low-risk peers.

In a study examining the influence of parental death and involvement in caregiving on distress in the daughters of breast cancer patients, Erblich et al. (2000) found higher levels of distress amongst daughters of breast cancer patients compared to women, who were not at elevated genetic risk of breast cancer. Specifically, daughters, whose mothers had died, reported significantly higher breast cancer related distress compared to daughters whose mother had survived and women with no genetic risk. The greatest level of distress and depression were observed in caregiving daughters whose mothers had died, whilst the highest levels of anxiety were seen in women whose mothers had died at a younger age (Erblich et al., 2000). The study by Erblich et al. also examined how perceived breast cancer risk contributed to psychological outcomes, finding that daughters, who perceived themselves to be at greater risk of breast cancer, reported higher levels of distress, regardless of the outcome of parental cancer (i.e., death or recovery) or their involvement in caregiving. This suggests that the threat to one’s own mortality is particularly salient for some adult children of breast cancer patients, independently of other cancer related stressors.
The increased psychological disturbance in first degree relatives of breast cancer patients may be evident in regard to cancer-related health behaviours. Valdimarsdottir et al. (1995) found that first degree relatives reported high levels of acute distress prior to having a mammogram; however, the distress was reduced to levels comparable with a low-risk cancer group once the women received normal results. In a study aimed at building a profile comparing depressed and non-depressed first degree relatives, Wellisch and Lindberg (2001) found that depressed first degree relatives feel much greater anxiety in relation to a range of cancer screening procedures, such as mammograms, pap smears and breast self-examinations. Importantly, this anxiety did not translate to lower levels of compliance with screening activities. It was, however, noted that depressed first degree relatives tend to over-estimate their risk of breast cancer, which may, in turn, contribute to sustained depressive symptoms (Wellisch & Lindberg, 2001).

The finding of increased distress and poorer psychological outcomes amongst daughters of breast cancer patients, while consistent, is not universal. For example, Wellisch, Gritz, Schain, Wang, and Siau (1991) found that daughters of breast cancer patients did not differ from matched controls in relation to their psychological symptoms, coping, preventative cancer activities and body-image. There were, however, significant differences in relation to their feelings of vulnerability to breast cancer (Wellisch et al., 1991), suggesting that the daughters of breast cancer patients are increasingly concerned about their future cancer risk.

Finally, in relation to first degree relatives of breast cancer patients, there is some suggestion that maternal breast cancer is stressful enough to elicit post-traumatic stress disorder (PTSD). It is argued that maternal breast cancer constitutes a “double traumatic stressor” (Wellisch & Lindberg, 2001, p. 334), as it threatens both a primary attachment and the individual. Furthermore, the individual both witnesses the trauma and life threatening nature of the disease in their mother, whilst simultaneously processing their own personal vulnerability to breast cancer in the context of an uncertain future (Lindberg & Wellisch 2004). To investigate the possibility of
traumatic stress reactions in first degree relatives of breast cancer patients, Lindberg and Wellisch (2004) surveyed 73 first degree relatives \( n = 60 \) daughters and found that 4% of their sample reported symptoms to meet the diagnostic criteria for PTSD, and a further 7% reported sub-clinical levels of PTSD. This finding is comparable to national prevalence rates in Australia, with estimates of 12-month prevalence rates suggesting that 5% of Australian are affected by PTSD (Australian Centre for Posttraumatic Mental Health, 2007). Furthermore, Lindberg and Wellisch concluded that the prevalence of PTSD-like symptoms were very similar to studies of cancer patients, strengthening the contention that witnessing cancer in a first degree relative and perceiving a high personal risk of cancer is as traumatic as experiencing cancer firsthand. Boyer et al. (2002) reported a higher proportion of participants with posttraumatic stress disorder, with 13% of the daughters in their sample reporting PTSD symptoms, while 94% of their sample indicated that they perceived their mother’s breast cancer as a traumatic experience. Startlingly, 85% of the sample of daughters demonstrated a partial PTSD pattern (i.e., meeting at least two of the three PTSD symptom clusters; Boyer et al., 2002). It was also found that, if the daughter’s mother also reported PTSD symptoms, it was significantly more likely that the daughter would report PTSD symptoms, suggesting that there may be some intergenerational pattern in the reaction to breast cancer (Boyer et al., 2002).

In a review of the literature into the psychological impact of parental cancer in adulthood, Mosher and Danoff-Burg (2005) concluded that a “sizeable minority of adult children of cancer patients experience psychological distress in terms of anxiety, depression, and posttraumatic stress symptoms” (p. 365). However, they identify several limitations with the current literature, including the lack of evidence for men facing parental cancer, the frequent lack of comparison groups, and the need to determine what role cancer type plays in the development of distress, and particularly posttraumatic stress (Mosher & Danoff-Burg, 2005). Perhaps the most scathing criticism that Mosher and Danoff-Burg propose is the failure of existing research to examine psychological strength in adults whose parents have cancer. Indeed, while psychopathology emerges in a “sizeable
minority,” it may be argued then that the majority of adults, whose parents have cancer, emerge from the experience with positive psychosocial adjustment. The ability to adapt to this stressor, and indeed re-interpret it as an experience from which personal growth has been achieved, has not been widely examined in the current literature. It is this possibility of personal growth, or benefit finding, that is the central variable in this thesis, and the remainder of this chapter will examine the empirical evidence to suggest that benefit finding is an outcome of the parental cancer experience.

2.3. Benefit Finding in Cancer – A Positive Possibility?

Benefit finding is conceptually embedded within the theoretical field of trauma related growth (for further theoretical details, please see Chapter 3), and essentially constitutes being able to find something good in a bad situation. However, before examining the possibility of benefit finding in cancer, it must first be established that cancer can be considered a traumatic stressor great enough to bring forth a posttraumatic growth outcome. Many studies examining posttraumatic growth have examined acute stressors, such as natural disasters, sexual assaults, transport accidents, and violent attacks (e.g., Frazier, Conlon & Glaser, 2001; McMillen, Smith & Fisher, 1997; Shakespeare-Finch & Armstrong, 2010). These events are typically a singular event arising from the external environment, with a clear onset and termination. Furthermore, such events have occurred in the person’s past and are viewed as being outside the control of the individual (M. Y. Smith, Redd, Peyser, & Vogl, 1999; Sumalla, Ochoa, & Blanco, 2009). Cancer, however, contradicts all of the features of an acute traumatic stressor in that it is complex, consisting not of one event but a series of events (e.g., testing, diagnosis, treatment, telling family, bodily changes and disfigurement, recurrence, spreading), the stressor is internal to the individual, the threat is on-going (even after successful treatment there may be fear of recurrence), there is a future rather than past orientation, and there is some sense of control relating to treatment and preventative behaviours (M. Y. Smith et al., 1999; Sumalla et al., 2009).

Despite the marked differences between cancer and acute traumatic stressors, the evidence suggests that the affective reactions to cancer are
very similar to those to acute stressors. Patients report feelings of fear, horror, shock and helplessness (Krause, 1991; M. Y. Smith et al., 1999). The affective reaction may then be exacerbated by a variety of physical experiences associated with the disease and its treatment, such as intense nausea, pain, and hair loss, which increase the intensity of the trauma (M. Y. Smith et al., 1999). In further support of the contention that cancer is a traumatic experience, there is also evidence to suggest that re-exposure to treatment related cues can elicit strong negative reactions, including nightmares, intrusive thoughts and avoidance behaviours (Redd, Dadds, Futterman, Taylor, & Bovbjerg, 1993; M. Y. Smith et al., 1999). Taken together, this evidence seems to strongly suggest that cancer is a traumatic stressor and, in 1994, the American Psychiatric Association (APA) included cancer as a stressor carrying the potential to result in PTSD.

Now it is established that cancer can elicit PTSD, it can be asked whether posttraumatic growth and benefit finding also occur in response to the illness. Benefit finding may be defined as “assigning positive value or significance to the event … learning about one’s strength in the face of adversity, or gaining insight into the meaning of life or the importance of relationships …” (Davis, Nolen-Hoeksema, & Larson, 1998, p. 562). Importantly, benefit finding represents a perceived enhancement of pre-trauma functioning, so it is not simply coping with the event, but rather constitutes the individual perceiving that beneficial personal change has occurred (Barskova & Oesterreich, 2009). There are various conceptualisations of benefit finding, and the types of benefits and the structure of the concept are still widely debated (e.g., Coyne & Tennen, 2010; Weaver, Llabre, Lechner, Penedo & Antoni, 2008). It is however usually accepted that perceived benefits may be classified into three groups: (a) benefits associated with interpersonal relationships, (b) benefits associated with life perspective, and (c) benefits associated with self (Thornton, 2002).³

³ Cancer as a potential stressor for PTSD remains in the current Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, APA, 2000).

⁴ This classification system is very similar to the domains of posttraumatic growth proposed in the theory by Tedeschi and Calhoun (1995, 2004, see Chapter 3, Section 3.1.2). Thornton’s framework has been used in the latter sections of this chapter, as it relates specifically to the field of cancer research.
There is a growing body of evidence to suggest that cancer patients commonly perceive that they have derived some degree of posttraumatic growth or benefit finding from their experience with the disease. Much of the research in the area has been conducted on breast cancer patients, with multiple authors (e.g., Bellizzi & Blank, 2006; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Sears, Stanton, & Danoff-Burg, 2003; Tartaro et al., 2005; Weiss, 2002), consistently highlighting that growth occurs in response to breast cancer. There is also increasing evidence of posttraumatic growth in samples of colorectal cancer patients (e.g., Salsman, Segerstrom, Brechting, Carlson, & Andrykowski, 2009) and samples of mixed cancer diagnoses examining benefit finding after surgery (e.g., Schulz & Mohamed, 2004; Schwarzer, Luszczynska, Boehmer, Taubert, & Knoll, 2006). Importantly, there is also evidence to suggest that posttraumatic growth and benefit finding are long-term phenomenon (e.g., Carver & Antoni, 2004; Lelorain, Bonnaud-Antignac, & Florin, 2010), with patients reporting positive changes as long as 15 years after diagnosis. Specifically, Lelorain et al. (2010) examined posttraumatic growth in over 300 disease-free breast cancer patients 5-15 years post diagnosis, and found that the patients’ reported levels of posttraumatic growth were comparable to the findings of shorter-term studies (i.e., within 5 years of diagnosis). This result suggests that the growth arising from the cancer experience is sustained over long periods, and may influence the individual’s psychological outcomes.

However, while research consistently indicates that benefit finding occurs in cancer patients, the results regarding predictors of benefit finding, and the role of benefit finding on psychological functioning, are ambiguous. In terms of predictors of benefit finding, the role of demographic variables is unclear, with Lechner and Weaver (2009) concluding that there is no consistent relationship between sociodemographic variables and benefit finding. On the other hand, Barskova and Oesterreich (2009) suggested that younger patients and women may report higher levels of posttraumatic growth. Other variables that are consistently related to posttraumatic growth and benefit finding are optimism, active or approach-orientated coping, and
social support, although the mechanisms through which such variables influence benefit finding are unclear (Barskova & Oesterreich, 2009; Lechner & Weaver, 2009).

In relation to psychological outcomes, much research has focused on the relationship between posttraumatic growth and benefit finding, with depression, anxiety, PTSD symptoms (e.g., intrusive thoughts) and well-being, typically with mixed results. In terms of depression, some researchers have found a relationship between benefit finding and depression, while others fail to find any relationship between the variables at all. For example, Helgeson, Reynolds, and Tomich (2006) concluded in their meta analysis that benefit findings was associated with lower levels of depression. On the other hand, a literature review by Zoellner and Maercker (2006) concluded that there was no systematic relationship between the two variables. In terms of anxiety, the general consensus is that anxiety is unrelated to posttraumatic growth or benefit finding (e.g., Dunn, Occhipinti, Campbell, Ferguson, & Chambers, 2011; Helgeson et al., 2006; Salsman et al., 2009; Zoellner & Maercker, 2006), however, recent research has challenged this conclusion. For example, Loiselle, Devine, Reed-Knight, and Blount (2011) examined the relationship between posttraumatic growth and state and trait anxiety, concluding that trait anxiety was negatively related to posttraumatic growth. It is suggested by this relationship that individuals with higher levels of trait anxiety are likely to have threat orientated schemas, and so the stressor does not challenge their core assumptions, but rather confirms them (Loiselle et al., 2011). Adding to the debate regarding posttraumatic growth and anxiety, Boals, Steward, and Schuettler (2010) found that, if analyses are only performed on traumatic stressors nominated as central to the participant’s identity, previously non-significant relationships between anxiety and growth become significant. In the light of these recent findings, it seems evident that the relationship between posttraumatic growth and anxiety requires further attention. The relationship between posttraumatic growth or benefit finding, well-being and other measures of positive adjustment remains just as elusive, with many contradictory findings being reported (e.g., Coyne & Tennen, 2010; Stanton, Bower, & Low, 2006; Zoellner & Maercker, 2006).
While the above brief review indicates that benefit finding is a common occurrence in cancer patients, of central importance to this thesis is the question of whether benefit finding occurs in the family members of cancer patients. Returning to the literature reviewed earlier in Section 2.2, it is clear that parental cancer elicits negative emotional reactions, and there is the suggestion that it can result in a diagnosis of PTSD. Furthermore, the APA (2000) recognises that “witnessing an event that involves death, injury, or a threat to the physical integrity of another person … serious harm, or threat of death or injury experienced by a family member…” (p. 463) are stressors that may be traumatic enough to elicit PTSD and, therefore, may also be powerful enough to bring about posttraumatic growth, in which benefit finding may be an outcome. The finding that parental cancer is often perceived as more stressful by children than patients (Kissane et al., 1994; Edwards & Clarke, 2004), and that genetic risk may increase distress and elicit concerns about one’s own mortality, strengthen the argument that parental cancer is a traumatic stressor for adult children. The remainder of this chapter reviews the literature on posttraumatic growth and benefit finding among spouses and adult children of cancer patients. The literature on spouses is briefly reviewed first, as there has been significantly more research in that area compared with adult children, which is understandable considering their close relationship with the patient and the likelihood that the spouse will be the primary caregiver (Wagner, Bigatti, & Storniolo, 2006). The spousal studies are included in the review as they demonstrate that benefit finding is an outcome for family members, therefore suggesting that it may also be possible in adult children.

2.3.1. Benefit finding in the spouses of cancer patients.

The presence of posttraumatic growth in spouses has been confirmed in both male and female partners of cancer patients (e.g., Thornton & Perez, 2006; Weiss, 2002). In a survey that attempted to determine whether the spouses of breast cancer patients reported positive outcomes and growth, Weiss (2002) found that 88% of husbands reported significant, long-lasting positive changes. Areas of reported benefit included increased compassion, spending more time with their spouse, a recognition of personal strength,
and valuing life (Weiss, 2002). Interestingly in this study, 83% of the husbands reported negative changes, a level slightly lower than positive change, suggesting that more of the participants were aware of the positive outcomes that had arisen from this stressful period, or that the opportunities for growth had allowed the negative consequences to be balanced with positive outcomes. Importantly, in this study, the cancer patients were asked whether they believed their partners had displayed evidence of posttraumatic growth to determine whether the changes were objectively observable, rather than simply being a subjective feeling of change within the partner. The results suggest a high degree of corroboration between husband and wife reports of growth, suggesting that the positive changes are real and translate to objectively observable behaviours (Weiss, 2002).

Among the female spouses of prostate cancer patients, Thornton and Perez (2006) found that patients and spouses reported similar levels of posttraumatic growth. An examination of the relationship between growth and quality of life one year post-surgery, however, revealed that growth was unrelated to the quality of life for both patients and their spouses (Thornton & Perez, 2006).

There is some suggestion that the degree of posttraumatic growth that emerges in spouses is related to gender. In studies which have looked at female breast cancer patients with male spouses (e.g., Manne et al., 2004; Weiss, 2002), the pattern of the findings tends to be that spouses report growth that is significantly lower than the patients themselves. For example, in the study conducted by Weiss (2002), the female patient’s total growth score on the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996) was 60 compared to a spouse score of 46. It is also interesting to note that, in both of these studies, the spouses reported lower levels of growth on all of the posttraumatic growth domains (i.e., new possibilities, relating to others, personal strength, appreciation for life and spiritual change).

However, the study conducted by Thornton and Perez (2006) examining growth in prostate cancer patients and their female spouses found that patients and spouses reported similar levels of growth, with partners actually reporting slightly higher (but statistically non-significant) levels of both.

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5 Higher scores reflect higher levels of posttraumatic growth.
overall growth and on all growth domains. Together, these findings suggest that gender may be an important variable to consider when examining the degree of growth that arises in the family members of cancer patients.

In addition to quantifying posttraumatic growth in spouses, the researchers cited above have attempted to determine the demographic, situational, cognitive and coping variables that predict the degree of growth that spouses report. For example, Weiss (2004) found a significant relationship between spousal posttraumatic growth and the number of social supports outside of the marriage, the depth of marital commitment, perceived support within the marital relationship, level of posttraumatic growth reported by the patient, and whether the spouse reported a level of stressfulness surrounding the cancer diagnosis that would meet the DSM-IV criteria of a traumatic event. However, in multiple regression analysis, the variables that were determined to be significant predictors of growth were limited to the perceived depth of marital commitment, the presence of posttraumatic growth in the patient, and the spouse’s subjective stress meeting DSM-IV diagnostic criteria of a trauma, with those three variables explaining 42% of the variance in spousal posttraumatic growth (Weiss, 2004).

In contrast to Weiss (2004), who found no significant relationships with growth and demographic variables, Thornton and Perez (2006) have found that several demographic items are predictive of postrautmatic growth. Specifically, Thornton and Perez found that growth was, in part, predicted by the employment status of the patient (higher growth if the patient was employed) and the level of education of the spouse (higher growth in spouses with lower education levels). Manne et al. (2004) also suggest that age may predict the degree of posttraumatic growth, with higher levels of growth being evident in younger spouses.

The studies by Thornton and Perez (2006), and Manne et al. (2004) have also attempted to determine which coping variables are predictive of posttraumatic growth. A range of coping variables have been considered and include cognitive methods (e.g., search for meaning, avoidance, positive
reappraisal), emotional approaches (e.g., emotional expression, support coping, processing of emotions) and instrumental coping. Both Thornton and Perez, and Manne et al. found that positive reappraisal was predictive of posttraumatic growth, and furthermore Manne et al. suggest that this variable is essential in sustained growth over a period of 18 months. Other coping variables that were predictive of growth include the use of cancer-specific avoidance strategies until after treatment has occurred (Thornton & Perez, 2006) and higher levels of emotional processing (Manne et al., 2004). Interestingly, in the study conducted by Manne and colleagues, the cognitive and emotional variables that predicted growth in spouses were entirely different from the predictors of patient growth, suggesting that, while both partners may benefit from the cancer experience, the process that they undergo to achieve such outcomes is very different. This further suggests the need for greater knowledge about growth outcomes in adult children. Simply assuming that they go through a similar process of adjustment to patients and spouses may be incorrect.

From the review of the studies above, it is evident that a multitude of variables have been assessed in relation to predicting posttraumatic growth. However, to date, a clear predictive pattern has not emerged. Considering that research in this area is in its infancy, and that different variables were considered in each study, this is hardly surprising. Regardless of the conflicting findings, it can be concluded that there are several factors that are potentially predictive of posttraumatic growth in spouses, particularly perceived stressfulness, coping, social support and some demographic items (Manne et al., 2004; Thornton & Perez, 2006; Weiss, 2004). Further research is required in this area before firm conclusions can be drawn.

There is a range of other studies that support the notion that spouses may perceive benefits arising from the cancer experience, especially in two main areas – in regard to their relationships with others and by providing an opportunity to re-evaluate priorities. Several studies suggest that the marital relationship may be improved through the provision of reciprocal support during the stressful adaptations that need to arise in response to a cancer diagnosis in one partner. For example, Dorval et al. (2005) conducted a
A longitudinal study examining aspects of the marital relationship over a twelve month period for women recently diagnosed with breast cancer. This group found that 42% of their sample reported that the cancer experience had brought them closer together (i.e., both partners reported increased closeness), while only 1% of couples had both partners claiming that they had grown apart. The remaining couples either reported that there was no change in their relationship, or had one member reporting that they felt closer (Dorval et al., 2005). The increased level of perceived closeness in the relationship was predicted by several variables, including the patients providing advice to the spouse about coping, the spouse accompanying the patient to treatment, the spouse perceiving the patient as confident, and demonstrations of affection and tenderness, suggesting that the couple worked together as a team to take care of each other’s emotional needs during the cancer experience (Dorval et al., 2005).

There are also several qualitative studies that support the notion that couples do indeed become closer through the cancer experience. This has been conceptualised by the couples as being a team coping with the disease together (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000). This team approach often became central to the couple, as individuals recognised the importance of their relationship and their desire for it to continue. Additionally, couples described how their communication patterns improved (Gray et al., 2000), they had a subjective feeling of increased closeness (Winterling, Wasteson, Glimeluis, Sjödén, & Nordin, 2004) and they actively engaged in efforts to create special times to do “couple things” (Hilton, Crawford, & Tarko, 2000, p. 446). Indeed, Keitel, Cramer, and Zevon (1990) conclude in their review of the literature on spouses of cancer patients that the cancer experience may provide opportunities for partners to shift their focus away from the trivial aspects of married life to put more energy into their relationship.

The second major area in which spouses seem to develop is the opportunity to re-evaluate life priorities. Many of the studies have focused on the male partners of breast cancer patients, and suggest that there is a shift in the emphasis placed on work and a greater valuing of family life.
(Germino, Fife, & Funk, 1995; Hilton et al., 2000). Indeed, this re-evaluation provided both an active coping strategy to reduce the demands placed upon the partner, but also served as an opportunity to instigate beneficial changes that allowed recognition of the importance of family, and a redefinition of success that was unrelated to work (Germino, et al., 1995). For older couples, the cancer experience was a chance to re-evaluate retirement options and to begin new leisure activities that they had previously put off (Gray et al., 2000).

In summary, the existing literature strongly suggests that the partners of cancer patients are able to benefit from the cancer experience. This conclusion is supported by the levels of posttraumatic growth reported by spouses, and the insights gained from qualitative studies which suggest that changes within the marital relationship and the re-evaluation of life priorities are possible. The idea of spousal benefit finding as evidence of posttraumatic growth would be accepted by Tedeschi and Calhoun (1995; Calhoun & Tedeschi, 1999), who propose a broad definition of traumatic stressors, and believe that stressful events may produce vicarious posttraumatic growth in others. Furthermore, Thornton and Perez (2006) argue that the suffering that the spouse experiences, when their partner is diagnosed with a life threatening disease such as cancer, represents first hand, real suffering that threatens to abruptly change their world, and therefore they are candidates for posttraumatic growth. The question that remains is whether such growth is evident in other family members, such as the adult children of cancer patients.

2.3.2. Benefit finding in the adult children of cancer patients.

It is evident that spouses of cancer patients are able to derive benefit from their experience of cancer; however the question of whether the adult offspring of cancer patients also undergo such a growth process is largely unanswered. To the author’s knowledge, there has only been one study to date (Mosher, Danoff-Burg, & Brunker, 2006) which has aimed to address the question “do adult offspring derive benefits from their parent’s cancer?” Mosher et al. (2006) found evidence that daughters, whose mothers have had breast cancer, reported posttraumatic growth at levels similar to breast
cancer patients. However, this study did not detail the degree of growth on posttraumatic growth domains within the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996). As a result, this study provides very little information other than simply confirming that positive changes are possible in response to parental cancer. Furthermore, the sample size ($n = 30$) is small by quantitative standards, and therefore the results are best viewed as a suggestion that posttraumatic growth may be possible, rather than as conclusive evidence that growth is a by-product of parental cancer.

Another study by Leedham and Meyerowitz (1999) examined long-term responses to parental cancer in daughters, specifically looking at the long-term positive effects of this experience. The findings suggested that benefit finding in parental cancer was a common occurrence, with 93% of their sample of 45 daughters suggesting that cancer had led to at least one positive change in their life. The types of benefits identified in the study included change in outlook, such as living for the day, learning to be responsible, increased spirituality, personal strength, increased closeness in family relationships and improved family communication (Leedham & Meyerowitz, 1999). Importantly, a second study of 71 daughters found that there were no differences between daughters whose parent had cancer and comparison peers in terms of psychological functioning, which Leedham and Meyerowitz suggests indicates that parental cancer does not place children at significant risk of later psychological maladjustment. They did, however, note lasting subjective changes, mostly positive, that may be too subtle to be detected through standard measurement, and therefore it is unclear how these elements influence psychological functioning (Leedham & Meyerowitz, 1999). Once again, this study had important limitations with the sample. Specifically, the cancer experience had to occur during childhood or adolescence (mean age of diagnosis was 14 years), whilst the daughter was still living at home, sometimes 12 -16 years prior to data collection. The generalisability of the findings to the adult cohort should therefore be interpreted cautiously, as the disease was experienced during a developmental period in which the individual may have lacked the cognitive ability to comprehend their situation, whilst simultaneously facing a series of developmental challenges that characterise childhood and adolescence.
Finally, a qualitative study by Wong, Ussher, and Perez (2009) examined benefit finding in bereaved cancer caregivers, finding that growth did arise from this experience across multiple domains. Specifically, the majority of the participants identified an increased recognition of personal strength, reflected by sentiments such as caring for a terminally ill cancer patient provided an opportunity to learn what being strong meant, that strength was gained through accepting one’s circumstances, and that strength develops from having to perform tasks that participants never expected they would be able to perform (Wong et al., 2009). Other areas of benefits that were noted included positive changes in personal relationships (both with the patient and with others), and changes in their perspectives on life (Wong et al., 2009). While this study does provide some relevant insights into the cancer caring experience, only five of the 23 participants were adult child carers, and therefore the results must be interpreted cautiously when being applied to the adult child cohort.

In the light of the lack of literature specifically examining benefit finding in the adult children of cancer patients, several in-depth qualitative studies that examine the general experience of parental cancer were reviewed (Baxandall & Reddy, 1993; Oktay, 2005; Tarkan, 1999), as well as briefer reported qualitative studies (Ferrell, Ervin, Smith, Marek, & Melancon, 2002; Germino & Funk, 1993; Mellon, 2002). Specifically, the published data was reviewed for data extracts that match Thornton’s (2002) classification of benefit finding in cancer (i.e., benefits associated with interpersonal relationships, life perspective, and the self), whilst remaining open to the possibility that additional benefits might emerge. It is important to note that the majority of the studies reviewed contained transcripts and extracts taken from daughters whose mothers were suffering from breast cancer, and as such represent a skewed sample in that there is the absence of male voices, and the type of cancer under review is largely limited. It is also imperative to keep in mind that the following sections outline the present author’s interpretation of the published data, and as such the analysis is conducted without a first hand knowledge of the participants, and therefore
may not accurately represent their position on the possibility of benefit finding in parental cancer.

In her review of cancer patients, Thornton (2002) recognised that benefits associated with interpersonal relationships often arose from the individual’s battle with cancer. The benefits described by Thornton as fitting this category include improved relationships, increased closeness and caring, increased time allocated to personal relationships and an increased emphasis on family. From the qualitative studies reviewed, there is clear evidence to suggest that the adult children of cancer patients may experience benefit finding in the area of interpersonal relationships. These benefits arise across several domains (i.e., with the patient, other family members and significant others)

The data presented in the studies by Baxandall and Reddy (1993), Oktay (2005) and Tarkan (1999) demonstrated that enhanced closeness between the ill parent and the child is an important change that many undergo. This change often encompasses both the child’s desire to be closer to their ill parent (Baxandall & Reddy, 1993; Germino & Funk, 1993), and the subjective experience of perceived improvements in the level of closeness within the parent-child relationship (Oktay, 2005). Oktay details several cases in which daughters commented that they perceived their relationship with their ill mother to have increased in closeness, with one daughter stating “I admire my mother a whole lot more today than I did before ... I think I actually felt closer to her” (Oktay, 2005. p. 390).

The cases presented by both Oktay (2005) and Tarkan (1999) suggest that the enhanced closeness between parent and child was established through both verbal and physical means. Several participants acknowledged that there was improved communication between parent and child, often perceived as increased confiding in each other, while other children tried to learn more about their parents through storytelling and journaling (Oktay, 2005; Tarkan, 1999). For example, one participant in Tarkan’s study commented “I was like a sponge. Asked her as many questions as I could . . . asked her about past relationships, about sex, about
my dad …” (p. 33). Physical activities such as cuddling, massaging, care giving, and personal grooming were also important in the perceived change in closeness with one’s parent (Tarkan, 1999). As one daughter remarked “We used to get on the bed and we would snuggle with her, my brother too; we would comb her hair or help her put on her makeup. Mostly, I remember these physical moments” (Tarkan, 1999, p. 131).

In some of the case studies reviewed, the reported changes in relationships between mothers and daughters also reflected the desire by some children to provide their parent with greater insight into the adult they had become. For example, a participant in Tarkan’s (1999) study commented, “It made me feel a deeper connection to her. The cancer made me stop hiding so much of myself from her” (p. 26). For some, the desire to have their parent know more about themselves was achieved through conversations about relatively safe topics such as work and grandchildren (Tarkan, 1999), while for others deeper topics of conversation, such as religion, death and relationships, were discussed (Oktay, 2005). Importantly, such changes were perceived by the child as taking their relationship to a new level, one that was often more honest and open. Furthermore, there are case examples to suggest that this change seems unlikely to have occurred should the parent have remained healthy (Oktay, 2005).

The concepts of ‘making up for lost time’ (Tarkan, 1999), increased acceptance (Oktay, 2005) or healing old wounds (Baxandall & Reddy, 1993) were frequently mentioned in the qualitative literature, suggesting that having a parent with cancer may reduce the emphasis placed on old conflicts. Both Baxandall and Reddy (1993) and Tarkan (1999) present case examples demonstrating the resolution of long term conflicts, suggesting that the diagnosis of parental cancer was crucial in bringing forth psychological healing. Typically, the diagnosis of cancer originally increased the level of contact between the parent and child and, through this contact the relationship developed and changed into something more meaningful for both parties (Baxandall & Reddy, 1993; Tarkan, 1999). In a case presented by Tarkan, the daughter was initially resistant to being involved with her mother, and only returned to care for her after she was
telephoned by a third party to inform her of the seriousness of her mother’s illness. This daughter commented:

> Despite all the distance between us and the years we were apart, I was able to create a meaningful relationship with my mother. I am almost positive it had to do with her being ill. I don't think we would ever have had the relationship if she weren't sick. It was something I never expected to have with her. It was that mother-daughter thing that she wanted, and much more (Tarkan, 1999, p. 90).

In the case outlined by Baxandall and Reddy (1993), the daughter reflected “having dredged up some of those old angers, hostilities and the bitter sadness of our relationship, I discovered the love I felt for her too” (p. 128). In this case, the mother and daughter were unable to resolve their conflict through communication; however, their actions indicated they were reaching out for each other. Specifically, the mother presented the daughter with a magnolia tree and requested that she name it after her. The mother also liked to sew tapestry and began to sew ‘memorials’ for her family members. In this instance, the daughter selected a large tapestry for her mother to complete, even though she disliked the image, stating “… in my heart I was just hoping it would take her so long to finish it that she just could not die before it was done” (Baxandall & Reddy, 1993, p. 130). Taken together, these two cases provide a strong suggestion that parental cancer may act as a catalyst to repair previously strained relationships, a significant outcome that may be conceptualised as benefit finding.

The second major area of change in terms of interpersonal relationship pertains to relating to other family members or significant others, such as partners or friends. Potential benefits that were frequently present in the data of the reviewed studies included positive changes in the dynamics of interpersonal relationships, and a shift in the importance that the child placed on family (Mellon, 2002; Oktay, 2005; Tarkan, 1999). Just as the cancer diagnosis brought children closer to their ill parent, a similar phenomenon was observed with other family members, usually the other parent, and to a lesser extent siblings or extended family (Baxandall & Reddy, 1993; Oktay, 2005). This enhanced bond tended to grow out of increased contact with family, being a team in the provision of care, and the
extension of emotional and practical support to each other during the difficult times. For example, one daughter, who nursed her mother after she refused to continue treatment, stated “My dad was always there, supporting, caring, and helping. My sisters, particularly my eldest and youngest sisters, and my husband were there for me; they never failed to listen. One of my brothers was always quietly supportive” (Baxandall & Reddy, 1993, p. 141).

In some of the cases presented in the literature, parental cancer also acted as a catalyst for change in the child’s relationships with other people, either through bringing about a termination of the relationship, or an enhanced appreciation (Oktay, 2005; Tarkan 1999). For several of the reviewed cases, the experience of parental cancer brought to a head problems that existed in their romantic relationships (i.e., long-term boyfriends, marriages). Generally speaking, the children who terminated long-term relationships during their parents’ illness (or shortly after their death) did not look at this change as a negative outcome, but rather as a liberating opportunity or something that they should have addressed some time ago (Oktay, 2005).

The other way in which relationships with significant others changed was the sense of an increased appreciation of the importance of such connections. Tarkan (1999) reports on one daughter who recognised the support that her husband provided while she cared for her mother, resulting in a new closeness between the couple. For other adult children, the experience of parental cancer led to a general re-evaluation of the importance of personal relationships (Oktay, 2005; Tarkan 1999). As one woman stated

Before my mother's illness I was less conscious of others. Now I feel that connections are very important with my parents, brothers, my girlfriends, and my boyfriend; people are more important to me. I'm much more careful with people and more mindful of my friendships and my family (Tarkan, 1999, p. 133).

Oktay (2005) also details how, in one of her cases, the adult child recognised that their extended support group had played a critical role in how they had coped with their parent’s cancer. This acknowledgment was
accompanied by an increased emphasis on the value of one’s connections with others, seeing them as critical in one’s life. Taken together, the multiple cases indicating a positive change in interpersonal relationships, both within the family and with others, supports the contention that parental cancer can bring forth benefits for adult children.

A concept, which is strongly suggested in the studies by Oktay (2005) and Tarkan (1999), is an increased insight into the importance of family. Several examples are pertinent, as this increased appreciation of family took many forms and was often very subtle. In one case, in which the parents had divorced, the daughter recognised it was essential that she and her brother be close to her mother before she passed away (Tarkan, 1999). Another daughter realised the importance of the role that her mother had played in her growing up, and so left full-time work to be able to spend more time with her own children (Oktay, 2005). In another of the cases presented by Oktay, a daughter spent time learning about the history of their family from her dying mother, recording the stories on video tape, so that they could be viewed by the grandchildren who had not yet been born. Finally, in an investigation into the experience of ovarian cancer for family members, Ferrell et al. (2002) present the story of a family gathered around the deathbed of their dying mother. Whilst being together to watch over her, they reminisced and realised the importance of their shared histories. This daughter commented “In fact we almost didn’t notice it [her mother passing away] because we were busy being a family, sharing growing up memories and falling in love with our pasts, the good things” (Ferrell et al., 2002, p.274).

From examining the cases presented in the reviewed studies, it is possible to conclude that living through parental cancer can lead some individuals to recognise the importance of family, and to value it in ways that exceed their previous expectations. As one daughter commented “I think there’s nothing more important to me than family. I’ve always felt like family was the most important thing, but I feel that even more so now” (Oktay, 2005, p. 190). It may be suggested that this increased valuing of family may continue to enhance familial relationships, and alter the
priorities of these individuals in ways that have profoundly positive effects on their lives.

The second categorisation of benefits by Thornton (2002) pertains to changes in the patient’s life perspective. Some of the benefits included under this category are an altered outlook or life philosophy, and changes in one’s life goals or priorities (Thornton, 2002). From the small sample of studies included in this review, it is evident that the same benefits are present in the adult children of cancer patients, and each of these is outlined below.

The notion of changing one’s perspective of how they viewed life was a recurring theme in the data presented by Oktay (2005), Tarkan (1999) and Mellon (2002). One daughter reflected, “breast cancer put everything into perspective in my life” (Tarkan, 1999, p. 122). In several cases, there was a new outlook that conceptualised life as a gift, leading to statements such as “life is an adventure” (Oktay, 2005, p.373), that one should “…take advantage of everything that life has” (Oktay, 2005, p. 191), and “live life to the fullest - don’t wait” (Mellon, 2002, p. 1120). Oktay also found that several of her participants recognised that they often engaged in activities that they did not enjoy, because it was what others expected them to do. As a result of their experience with parental cancer, some of the children made the commitment to cease this, and grab hold of activities that they themselves enjoyed (Oktay, 2005).

Another frequently reported positive change to emerge from living through parental cancer was a clear shift in the adult child’s priorities. The two main areas of changed priorities, identified by Baxandall and Reddy (1993), Oktay (2005) and Tarkan (1999), were in relation to work and family. In regard to changing work priorities, the increased insight that life is temporary and too short to waste doing things you do not enjoy led several individuals to change their vocational focus (Oktay, 2005; Tarkan, 1999). Several participants left jobs they had found unfulfilling or demeaning, with one daughter stating “I feel like her death maybe was the impetus for me to get on with my life and do things that would make me
happier in my career” (Oktay, 2005, p. 190). For another daughter, who lost her mother to breast cancer, the experience opened up a whole new vocational pathway when she went into business, and opened a healing centre aimed at providing cancer patients with alternative and complementary therapies (Tarkan, 1999).

The studies by Baxandall and Reddy (1993) and Oktay (2005) suggest that altered priorities in terms of family are evident, either in the form of changes to the work-home balance, or an increased emphasis on starting a family. Some participants decided to change their home-work balance, changing to part-time work to ensure that they were able to be more involved in their children’s lives. For example, one daughter who left her office job to retrain as a part-time youth minister commented,

I wanted to be a part of my children’s lives, just like my mum was part of my life. That means not working a sixty-hour-week job. It means being home during the day, being the den mother, being their coach, doing the sports, running them around, and being an active part of their life. I want a career, but I had to realign my priorities (Oktay, 2005, p. 205).

For other individuals, facing the loss of a parent made them consider the importance of family, and how they would indeed like to start a family of their own. Some daughters were regretful that they had left it too late to start their families, fearing that their children would not know their grandparents (Oktay, 2005). Consequently, these adult children frequently took steps to ensure that their children shared some connection with their grandparents (e.g., video tapes, journals). For one daughter, the realisation that she had the ability to unconditionally love and care for her sick mother made her realise that she could be a loving parent, leading to her decision to start a family, something she thought that she never had the capacity to do (Baxandall & Reddy, 1993).

The final category of benefits identified by Thornton (2002) relates to benefits associated with the self. This is a highly subjective category, including benefits such as increased inner strength, independence, improved self-worth, satisfaction with life accomplishments and maturation.
(Thornton, 2002). After reviewing the studies conducted by Baxandall and Reddy (1993), Oktay (2005) and Tarkan (1999), it is evident that some adults, whose parents have cancer, engage in a highly personal journey that leads to significant personal changes, particularly in the areas of recognising the importance of self, personal strength and personal growth.

Oktay (2005) and Tarkan (1999) both present cases in which parental cancer led the adult child to recognise the need to nurture the self, and in doing so acknowledge their own needs. This recognition took several forms, including the commitment to focus on one’s own needs rather than always putting the needs of others first, actively engaging in activities designed to increase personal happiness (Oktay, 2005), and participating in nurturing activities, such as yoga and meditation, aimed at reducing anxiety and fear (Tarkan, 1999).

There is also evidence in the case studies to suggest that parental cancer can bring about positive changes in health behaviours. There are two distinct types of behavioural change: firstly, a general change in daily health activities that are aimed at improving overall well-being (Oktay, 2005), and secondly, the engagement in activities that are specifically designed to prevent the individual from developing cancer (Oktay, 2005; Tarkan, 1999). The general health changes that the adults mentioned in the Oktay (2005) study included: commencing a daily exercise program, avoiding smoking, minimising drinking, dietary changes, using vitamin supplements, stress reduction activities and a general perception that one needs to be more aware of one’s health. In terms of cancer specific health behaviours, there is evidence to suggest that parental cancer may prompt some children to engage in regular preventative activities, such as conducting breast self-examinations and having regular mammograms (Oktay, 2005). Genetic screening to determine breast cancer risk has also been reported in some cases (Tarkan, 1999). In addition, individuals have engaged in further preventative actions, including establishing a relationship with a breast specialist for regular reviews and participating in breast cancer prevention research (Tarkan, 1999). Consequently, from the evidence in these studies, it is clear that parental cancer can lead to beneficial changes in the
individual’s health practices, both in terms of immediate health promotion and in long-term preventative efforts.

Through battling with their parent’s cancer, several of the adults participating in the studies by Oktay (2005) and Tarkan (1999) became aware of their personal strength. Some daughters reported feeling that they had to be strong to help hold the family together, while others found that their strength was imperative to their own coping efforts (Tarkan, 1999). Oktay found that some participants were made aware of strengths they already possessed, while for others the cancer journey was explicitly seen as the time in which they developed their personal strength, through the process of learning about themselves and coping with great adversity. As one daughter, who lost her mother to breast cancer, commented “I kind of use my mother’s death to weigh things against. I think, if I can get through losing my mother, I can get through this” (Oktay, 2005, p. 376).

The idea of growing through the experience of parental cancer was identified as central to several of the cases outlined by Oktay (2005) and Tarkan (1999), often involving themes of maturation and the recognition of change in oneself since the cancer diagnosis. Interestingly several of the daughters directly attributed their changes to their mother’s breast cancer, as one daughter states “… I used it as an opportunity to grow. I really became a different person…. The change has been extraordinary” (Tarkan, 1999, p. 132). Whilst most of the participants who recognised personal growth described it in positive terms, some recognised that the experience had made them feel less vibrant and bubbly. However, they still recognised the growth as pivotal to their maturity and newfound sense of responsibility (Tarkan, 1999). Indeed, Tarkan describes a case in which the child conceptualised her mother’s struggle with cancer as a learning opportunity that she would be negligent not to take. Through acknowledgment of her growth resulting from her mother’s illness, she was able to find meaning in her experience, and was able to positively reframe her interpretation of it, as represented in her comments:

What is the point of this unless you can come out of it having grown, or having learned, or being available for someone else who is going through a similar situation? I don’t feel
I feel really powerful in that I will be able to face anything that comes my way (Tarkan, 1999, p. 135).

For other participants, this sense of growth took the form of emotional maturation, with changes described as becoming more caring, more compassionate and more empathetic (Oktay, 2005; Tarkan, 1999). For others, emotional growth signified a change in their reactivity, noting that the little things were no longer as upsetting as they used to be, and there was a letting go of past angers (Baxandall & Reddy, 1993; Oktay, 2005; Tarkan, 1999).

Some of the case studies suggested that the personal development that individuals felt, arising from their parent’s cancer, was demonstrated through supporting various helping and advocacy organisations (Oktay, 2005; Tarkan, 1999). While overwhelmingly the majority of such activities were linked to cancer organisations, there were also examples of engagement in general counselling and women’s organisations/centres that did not have a specific cancer focus (Oktay, 2005). The daughters of breast cancer patients reported a variety of ways in which they contributed to cancer causes. For some daughters, financial contributions were made to organisations (e.g., weekly contributions, attending fundraisers, establishing a scholarship; Oktay, 2005), whilst others made a donation of time and skills. This voluntary activity often involved supporting patients with their disease through self-help groups, hospice care, organising cancer events and the provision of cancer-related education material (Oktay, 2005; Tarkan, 1999). From the reviewed cases, it was clearly evident that parental cancer had motivated the adult children to get involved in activities that assisted other people, and it may be suggested that the motivating factor was their personal experience with parental cancer.

As can be seen from the synthesis of findings and data extracts presented from the reviewed studies, there is clear evidence to suggest that benefit finding is a possible outcome arising from parental cancer, even though the researchers were not examining their data with a focus on benefit finding. The presented examples suggest that benefit finding arises across multiple domains, and the types of benefits reported by adult children seem
to have a high degree of similarity to the types of benefits reported by cancer patients themselves, as was seen by the applicability of Thornton’s (2002) classifications to the types of benefits presented in the reviewed studies.

The above detailing of previously reported data is crucial, as it provides evidence that benefit finding is possible in parental cancer, and it provides some insight into the type of benefits that arise. It is, however, important to note that there were numerous cases presented in the studies that included no evidence of benefit finding. Specifically, Oktay (2005) presented 19 case studies, in which the review above identified possible benefits in 12 (63%) of them, Tarkan (1999) presented 16 case studies with nine (56%) showing evidence of benefit finding, while Baxandall and Reddy (1993) presented four cases, of which three (75%) had participants reporting positive outcomes. Therefore, caution should be taken when considering the extent to which benefit finding occurs for adults whose parents have cancer, and it is noted that there will be individuals who do not experience any posttraumatic growth from their parent’s illness. Despite this, it does highlight that this area is an avenue in need of further investigation. Therefore, this thesis seeks to establish that benefit finding is possible in adults whose parents have cancer, examine the types of benefits that are reported by this group, and identify variables that may be predictive of benefit finding. It is also important to consider the role that benefit finding may play in the adult child’s psychological outcomes in response to their parent’s cancer.

In summary, this chapter has examined the incidence and prevalence of cancer in Australia, and established the argument that parental cancer is particularly relevant to adult children, despite a lack of research in this area. Most of the existing research has examined negative psychological outcomes of parental cancer, with the research suggesting that poor psychological functioning, particularly in terms of depression, anxiety and posttraumatic stress disorder, are possible outcomes. Such a narrow focus on psychopathology is criticised as limiting our understanding of the potential range of psychological outcomes from the parental cancer.
experience, as it has ignored the possibility of positive outcomes, such as benefit finding. There is clear evidence from research into cancer patients and their spouses that posttraumatic growth and benefit finding are possible outcomes. However, to date there has been very limited research conducted into the area of benefit finding and parental cancer with an adult child cohort. Consequently, this thesis aims to expand the knowledge in this area.
Chapter 3: Theories of Posttraumatic Growth

Historically, psychology has tended to focus on the development of psychological problems, such as posttraumatic stress disorder, as a response to trauma and crisis (Joseph, Linley, & Harris, 2005). However, there is growing evidence and theory building surrounding the notion of growth from adversity. While each proposed growth theory is subtly different, a common underlying foundation is the need for psychological restructuring or re-interpretation of the traumatic event and one’s world to enable the individual to view their experience as beneficial and meaningful (Affleck & Tennen, 1996). As such, the event must be sufficiently stressful so that the individual perceives a discrepancy between the event and their long-held views of self and the world. The basic model of growth, which represents the core process of most growth theories, can be represented pictorially as follows:

![Diagram of the model of posttraumatic growth]

Figure 3.1. Model of posttraumatic growth as summarised by Park (2009).
In recent years, there has emerged a classification of growth theories into one of two categories: (a) growth as an outcome (or construction) of the traumatic event, or (b) growth as an illusion (or a coping strategy; Sumalla et al., 2009; Zoellner & Maercker, 2006). Theories that position growth as an outcome typically hold the view that, in the light of an extreme challenge, individuals must alter their long-held beliefs and goals so that they are consistent with new information they have obtained from the trauma (a process of accommodation; Park, 2009). On the other hand, theories that view growth as a coping mechanism propose that individuals need to alter their view of the stressor, so that it aligns with their long-held global meaning (a process of assimilation; Park, 2009).

This chapter reviews three of the main theories of trauma-related growth, with a focus on the work of Janoff-Bulman (1989, 1992), Tedeschi and Calhoun (1995), and Taylor (1983). The chapter then examines the current debates within the posttraumatic growth literature, highlighting conceptual concerns within the field. Specifically, arguments will be presented relating to conceptual ambiguity and issues with terminology, the lack of clarity in empirical findings regarding the relationship between posttraumatic growth and psychological adjustment, and issues relating to the measurement of the concept. Finally, the chapter pulls together the theoretical information presented in this chapter with the empirical findings presented in Chapter 2 to put forward a clear statement of the research aims of Study One.

3.1 Posttraumatic Growth as an Outcome

3.1.1 Janoff-Bulman’s Social Cognitive Theory: The assumptive world.

In the social-cognitive theory proposed by Janoff-Bulman (1989, 1992), it is argued that people’s lives are guided largely by a set of cognitive assumptions. These assumptions represent a conceptual schema which “provide a basis for anticipating the future and guide what we notice and remember, as well as how we interpret new information” (Janoff-Bulman, 1989, p. 115). It is proposed that these assumptions develop over time, and are rooted in our early childhood experiences. As such, they are the most
abstract of our cognitive beliefs, and also the beliefs of which we are the least aware (Janoff-Bulman, 1992).

The three most fundamental assumptions include: a belief in a benevolent world; the existence of a meaningful world; and that one is a worthwhile individual (Janoff-Bulman & Berger, 2000; Janoff-Bulman & Frieze, 1983). The belief in a benevolent world refers to our understanding of people and events. Generally, we believe that other people are good, and that there are a greater number of positive events than negative events (Janoff-Bulman, 1992). It is noted that people can still maintain this belief, even if they are pessimistic about the wider world. For instance, they may hold the belief that the current political troubles in the global world are negative, yet still believe that their world (what directly happens to them and the people they have contact with) is benevolent, and therefore good things will happen to them. The second assumption, the view of a meaningful world, rests with beliefs about why events happen to particular people (Janoff-Bulman, 1989, 1992). Specifically, good and bad outcomes can be explained by the nature of the people involved: good things happen to good people, while bad things happen to bad people. This belief is deeply rooted in the Western notions of justice and control, and asserts that events are not random, but are rather driven by some form of “person-outcome contingency” (Janoff-Bulman, 1992, p. 9). Finally, the assumption of self-worth recognises that people generally see themselves as good, moral and competent (Janoff-Bulman, 1992). This assumption is demonstrated in numerous ways, such as consistent reports that individuals perceive themselves to be better than others in terms of ability and personal qualities, that reported self-esteem is generally high, and that people tend to take credit for success rather than failure (Janoff-Bulman, 1992).

As stated earlier, these core assumptions develop during early childhood, where a safe environment and supportive experiences allow the individual to feel safe and protected. As we get older and our world expands, these early views of the world are carried with us, giving us a sense of confidence and trust (Janoff-Bulman, 1992). The main purpose of these assumptions is to provide the individual with stability through the
belief that the world is just and predictable, therefore allowing individuals to fulfill their functional potential (Janoff-Bulman, 2004; Janoff-Bulman & Frieze, 1983). However, they also lead to a sense of invulnerability, the illusion that bad things will not happen to ‘me’ (Janoff-Bulman, 1989). Like most cognitive schemas, the basic assumptions are typically resistant to disconfirmation and change (Affleck & Tennen, 1996), with the individual typically assimilating new information into the existing assumptions, rather than developing altered assumptions (Janoff-Bulman, 1989).

When traumatic events occur the core assumptions are unable to explain or assimilate the new information. According to Janoff-Bulman (1989, 1992; Janoff-Bulman & Frieze, 1983), traumatic and highly stressful events are powerful enough to shatter the assumptions that individuals hold about the world. In response to the destruction of one’s expected stability, individuals may experience intensely negative reactions including anxiety, depression, confusion and helplessness (Janoff-Bulman, 1989). They find themselves in a situation that brings into question their underpinning assumptions, in which the severity of the trauma makes it impossible for individuals to reconcile the discrepancy between the reality of their intensely stressful experience and the safety of their assumptive world. Furthermore, the intensity of the traumatic event is too powerful for the individual to assimilate it into the existing assumptions. Consequently, individuals face a situation in which they grieve for the loss of the old world, while facing the challenge of creating new cognitive schemas to accommodate their new experiences of the world. Arising from this turmoil is the opportunity for change and growth, as the individual must “rebuild their inner worlds” (Janoff-Bulman & Berger, 2000, p. 32) to accommodate not only the trauma they have undergone, but the realisation that the world may be dangerous and malevolent. The new assumptions will reflect the changes in beliefs about the world and self, and research by Janoff-Bulman (1992) has consistently shown that the assumptive worlds of trauma victims are more negative when compared to non-victims.

The means of rebuilding requires much cognitive processing and a switch from automatically processing information concerning the world to
intentional cognitive efforts, such as attending, noticing and attributing value, reinterpretation, and intrusive, recurrent thought, with the aim of re-establishing a world view that is meaningful (Janoff-Bulman & Berger, 2000; Joseph & Linley, 2005). It is through such processes that individuals may derive growth from their traumas, as they purposefully engage in cognitive reappraisals that emphasise the lessons that can derived from the experiences and focus on the positive by-products that have emerged (Affleck & Tennen, 1996; Janoff-Bulman, 1989). In essence, the individual recognises the value and specialness of elements of their life, and thereby increase their appreciation of it. For example, after undergoing invasive treatment for breast cancer, a woman may re-interpret her trauma by focussing on the valued support she received from her husband during her illness, her steely determination and the chance to spend more time with her children, rather than focussing on her pain, how close she came to death and how distraught she was at the time of diagnosis. The transformation from trauma to growth is possible, if the individual is able to “emphasise benevolence over malevolence, meaningfulness over randomness, and self-worth over self-abasement” (Janoff-Bulman, 1992, p. 133). The re-interpretation of the new experience as something positive allows the individual to hold onto much of their old assumptions, as the trauma is now perceived as a lesson learned, and that they have come through it as worthy people living in a benevolent, just world (Janoff-Bulman, 1989). There is also some suggestion that individuals, who originally held strong positive assumptions pre-trauma, may experience greater initial psychological disruption (due to greater violation of one’s core beliefs), but they have better long-term recovery. Specifically, such individuals may possess the psychological characteristics and environmental features required to cope with traumatic stressors, and therefore make the transition from meaningless world to meaningful life (Janoff-Bulman, 1992; Janoff-Bulman & Frantz, 1997).

In a further extension of the original theory, Janoff-Bulman (2004) proposes that growth arises out of three distinct models, namely strength through suffering, psychological preparedness and existential re-evaluation. These models are thought to represent distinct psychological processes that
give rise to posttraumatic growth. In essence, Janoff-Bulman argues that the concept of posttraumatic growth is multifaceted, and therefore should be examined as separate processes that lead to the outcome of growth. The first model, strength through suffering, suggests that inner reflection allows for the recognition of the trauma that has been experienced, accompanied by learning about one’s personal strengths, competencies and abilities. As such, it is an opportunity for new coping skills to develop and an increased awareness of new possibilities in life. In essence, this model proposes that the growth occurs through the creation of “new evaluations of the self” (Janoff-Bulman, 2004, p. 31), and the new belief that one will be able to cope with whatever life throws at them (Janoff-Bulman & Berger, 2000).

The second model of growth, psychological preparedness, is closely linked to changes in the individual’s assumptive world. While all individuals are aware that unfortunate events may happen, people generally live with the expectancy that such things will happen to others, and therefore are psychologically unprepared for trauma (Janoff-Bulman, 1989, 2004). When trauma occurs, individuals undergo an immense disconfirmation of their assumptions, and recognise that their psychological foundations were inadequate and inaccurate. After trauma, as they rebuild, individuals incorporate their new knowledge into their new schemas, and simultaneously make themselves better prepared for subsequent trauma, therefore minimising the potential for traumatisation (Janoff-Bulman, 2004). In essence, the trauma allows the development of a “secondary control” (Janoff-Bulman & Frantz, 1997, p. 102), in which they have developed an awareness of their strengths and the belief that they can triumph over future adversity.

The final proposed model of growth is existential re-evaluation, representing a new found appreciation for life overall and/or specific elements of it (e.g., family). The essential process involved in existential re-evaluation is meaning making. Specifically, Janoff-Bulman and Frantz (1997) argue that individuals engage in cognitive processing that is designed to allow the development of two types of meaning: meaning in the form of comprehensibility, and meaning in the form of personal significance. The
establishment of comprehension (i.e., why did this happen to me?) involves a process that combines rumination (both intentional and unintentional) with a confrontation of meaninglessness, which brings forth an acknowledgement that misfortune can affect individuals at any time (Janoff-Bulman, 2004; Janoff-Bulman & Frantz, 1997). The meaning of significance is established through asking questions that relate to worth, an acknowledgment that life is precious, and the development of an increased appreciation of life as individuals recognise that living should not be taken for granted. This change is demonstrated when individuals attend to areas of their lives in different ways, and pay attention to aspects of living previously ignored or undervalued (Janoff-Bulman, 2004). It is arguable that individuals need to undergo a trauma or psychological disruption of some description to allow themselves to realise that they have undervalued their life, that they do take life for granted, and that there is a need for greater appreciation of self and the world (Janoff-Bulman & Berger, 2000). At the conclusion of this process, individuals, through the post-trauma choices and commitments that they make, have “moved from concerns about the meaning of life to the creation of meaning in life” (Janoff-Bulman, 2004, p. 33).

As individuals progresses through one or any combination of the three models, they have experienced a process that leads them to develop a sense of appreciation that allows them to recognise what is valuable (and to create value in certain aspects of their life; Janoff-Bulman & Berger, 2000). Ultimately, this sense of appreciation will allow individuals to acknowledge the benefits that they have derived from their adversity, and therefore recognise the growth that they have achieved. Such a realisation can be empowering for individuals and may contribute to overall adjustment.


The growth theory proposed by Tedeschi and Calhoun (1995, 2004) is closely related to the work of Janoff-Bulman (1989, 1992, 2004) and her colleagues (Janoff-Bulman & Frieze, 1983; Janoff-Bulman & Frantz, 1997), in that it builds upon the notion that trauma may pose a severe challenge to the individual’s assumptive world (Calhoun & Tedeschi, 2004). The underlying premise of the theory is that traumatic stressors pose a
significant challenge to the individual’s “ability to order, make sense of, and find meaning in their lives” (Calhoun & Tedeschi, 1999, p. 2). This theory of posttraumatic growth proposes that growth is one possible outcome in response to traumatic stressors, with growth being defined as “positive change that the individual experiences as a result of the struggle with a traumatic event” (Calhoun & Tedeschi, 1999, p. 11). Importantly, Calhoun and Tedeschi (1999) propose a wide definition of trauma, arguing that trauma includes not only events classified as antecedents of PTSD, but rather any emotionally overwhelming event, a classification for which parental cancer would seem to qualify. Despite this broader definition of trauma, the event must be significant enough to represent real challenge to the assumptive world, otherwise growth is unlikely to occur (Lindstrom, Cann, Calhoun, & Tedeschi, 2011).

Under this theory, growth arises from extensive cognitive processing of the trauma and its implications for the individual. In this sense, growth is not linked directly to the traumatic experience itself, but rather arises from the individual’s struggle to process and make sense of their new reality. Significantly, Tedeschi and Calhoun (2004) argue that crisis events are highly emotional, and this affective aspect is what makes them transformative. If the event did not bring forth strong emotional reactions, the ‘lessons learnt’ would not have such a profound effect but rather represent “mer[e] intellectual reflections” (Tedeschi & Calhoun, 2004, p. 5). It is also thought that the intense emotional aspects differentiate posttraumatic growth from normal developmental processes, such as maturation. Tedeschi and Calhoun (2004) also argue that posttraumatic growth is not simply a return to pre-trauma functioning and psychological status, but rather growth constitutes an improvement in some area of the individual’s life. Furthermore, the theorists argue that posttraumatic growth is not synonymous with coping, as growth represents an outcome or ongoing process, rather than a coping strategy (Tedeschi & Calhoun, 2004). Indeed, coping efforts in the form of social support and cognitive rebuilding, in a way that produces schemas which can accommodate the present and potential future traumas, may play an important role in the development of post-traumatic growth (Tedeschi & Calhoun, 2004).
Growth emerges largely through two cognitive processes: namely ruminaton and the formation of a life narrative that incorporates the traumatic event and one’s journey through it (Calhoun & Tedeschi, 1999; Tedeschi & Calhoun, 2004). Whilst rumination is almost universally accepted as being strongly linked to depression and other negative affective states (e.g., Just & Alloy, 1997; Nolen-Hoeksema, 2000; Nolen-Hoeksema, Morrow & Fredrickson, 1993; Spasojevic & Alloy, 2001), Tedeschi and Calhoun (2004) adopt the suggestion by L. L. Martin and Tesser (1996) that there may be positive forms of rumination, such as problem solving, reminiscence and anticipation. The theory of posttraumatic growth suggests that, in the early stages after trauma, an individual may engage in largely automatic and intrusive rumination, which is indicative of early cognitive processing (Joseph & Linley, 2005; Tedeschi & Calhoun, 2004). At a later stage in the process, the positive aspects of rumination are utilised, which allows the individual to engage in deliberate, effortful cognitive processing, which is seen as imperative to the development of posttraumatic growth (Tedeschi & Calhoun, 2004). This deliberate rumination may allow the individual to let go of previously held beliefs, goals and activities, which in turn ‘makes way’ for growth to occur (Calhoun & Tedeschi, 1999). Growth is especially likely if the content of the ruminative thoughts involves reflection upon favourable past events, the individual’s attempts at coping with the trauma, and a search for meaning in the traumatic event (Calhoun & Tedeschi, 1999). There is empirical support for the suggestion that deliberate cognitive processing of negative events gives rise to growth. For example, Ullrich and Lutgendorf (2002) found that participants, who were instructed to write a journal about emotions and cognitive processing after traumatic events, reported greater growth than participants who only wrote about emotional aspects.

The second cognitive process linked to posttraumatic growth, narrative development, is largely focused on addressing the questions of how the trauma has altered the individual’s identity and their life story (Calhoun & Tedeschi, 1999). Typically, trauma narratives divide one’s life into before and after the trauma, and include the notion of the trauma as a
turning point (McAdams, Reynolds, Lewis, Patten, & Bowman, 2001; Tedeschi & Calhoun, 2004). The construction of narrative is seen as important in making sense of the event and in the development of life wisdom (Calhoun & Tedeschi, 1999), both seen as essential elements in growth.

Tedeschi and Calhoun (1995) have categorised the types of growth that emerge into three broad categories, namely self-perception, interpersonal relationships and philosophy of life. This classification matches the classification of benefits found in cancer patients proposed by Thornton (2002, see Section 2.3), which supports the argument that serious illness is a stressor capable of bringing forth posttraumatic growth. The first category of growth, positive changes in self-perception, is associated with the recognition of personal strength, but also an acknowledgement of vulnerability that may contribute to a more accurate perception of the world (Calhoun & Tedeschi, 1999). This area of growth typically encompasses changes such as feeling stronger, increased self-assurance, and a greater sense of resilience. This category of growth is well supported in the trauma literature, with many studies consistently finding that this is one of the more common areas of growth. For example, perceptions of increased personal strength were found to be a common area of growth in a study by Shakespeare-Finch and Armstrong (2010), which compared areas of growth with types of trauma (sexual assault, bereavement, and motor vehicle accident). Studies of domestic (Young, 2007) and community violence (Updegraff & Marshall, 2005) have also found that personal strength and confidence are reported as areas of significant growth. Finally, Weiss (2002) identified personal strength as one of the key areas of growth in the spouses of breast cancer patients. Tedeschi and Calhoun (1995) argue that the lived experience of trauma provides the individual with an immense amount of information regarding their ability to cope with intense stressors and their self-reliance.

The second area of growth is changes in relationships with others, which is characterised by a perceived strengthening of the relationship, enhanced communication, increased empathy for others, and the realisation
that others were available to support the individual when in need (Calhoun & Tedeschi, 1999; Tedeschi & Calhoun, 1995). This category of growth is again well-supported by research studies. For example, in a study of individuals disabled by chronic illness or traumatic injury Salick and Auerbach (2006) found that all of their participants \( n =10 \) reported an enhanced sense of empathy that had not been present prior to their disability. In her study of victims of domestic violence, Young (2007) reported improved relationships with others as the most significant area of growth for battered women, signified as multiple positive changes in both romantic and non-romantic relationships. Additionally, Harms and Talbot (2007) report that the most frequently endorsed aspect of growth in their study of motor accident victims was a recognition of social support.

The final category of growth is a changed philosophy of life, which encompasses elements such as greater appreciation of life, altered priorities, and enhanced spirituality. Often, this type of growth may assist in the development of a new sense of meaning in life, which is crucial for re-establishing order and purpose in the face of trauma (Tedeschi & Calhoun, 1995). The research support for this category of growth is mixed. There is strong support for the notion of an enhanced appreciation for life, with numerous studies finding this as the greatest area of positive change. For example, in the study by Ickovics et al. (2006) into urban adolescent females, it was found that greatest change was reported in an appreciation for life amongst all trauma categories (pregnancy/motherhood, death of a loved one, physical threat and interpersonal problems). Similarly, in a study on adults with Meniere’s disease, the domain of appreciation for life was most strongly endorsed (Dibb, 2009), whilst Shakespeare-Finch and Armstrong (2010) found that this area of growth was particularly salient for bereaved individuals. In a study of breast cancer patients, Petrie, Buick, Weinman, and Booth (1999) found that a greater appreciation for life and altered priorities were the second and third most commonly reported positive change after improved close relationships. There is, however, less support for the area of spiritual growth arising from trauma. For example, spiritual change was identified as the area of least growth in the studies by Dibb (2009) and Harms and Talbot (2007), while Ickovics (2006)
eliminated the spiritual growth items from their instrument, as pilot testing showed that they lacked relevance to the target cohort (i.e., urban adolescents). There are, however, studies that show that spiritual change is important for many trauma survivors. For example, both B. W. Smith, Dalen, Bernard and Baumgartner (2008) and Updegraff and Marshall (2005) found that spirituality was an area of greater growth than relating to others.

In the advancement of research in the area of posttraumatic growth, Tedeschi and Calhoun (1996) constructed and validated the Posttraumatic Growth Inventory (PTGI). The original scale construction involved a literature review, and the construction of posttraumatic growth items based upon the themes extracted from existing empirical works. Through their work on the scale development, Tedeschi and Calhoun (1996) proposed that posttraumatic growth may occur across five domains: (a) greater appreciation of life, including possible changes to one’s priorities; (b) increased closeness in personal relationships; (c) increased recognition of one’s personal strengths; (d) awareness of new possibilities within one’s life; and (e) spiritual (both religious and/or existential) development. Importantly, Tedeschi and Calhoun (1996) were able to demonstrate that the growth derived from trauma were present at higher levels in trauma victims compared to non-trauma individuals (in all domains except religious/spiritual development), suggesting that the construct of posttraumatic growth is valid, and represents a process that is largely unique to individuals dealing with highly stressful events.

The PTGI has been used extensively in research since its development, examining posttraumatic growth in a variety of highly stressful circumstances (e.g., childhood sexual assault, serious illnesses such as cancer, HIV/AIDS and heart disease, diagnosis of severe foetal abnormality, motor vehicle accidents, bereavement, community violence, prisoners of war, and natural disasters). There has been some debate regarding the factor structure of the scale (see Joseph & Linley, 2008), but recent research by Taku, Cann, Calhoun, and Tedeschi (2008) has confirmed the original five factor structure. Specifically, using a large sample of over 900 participants, the researchers tested whether a 5-factor, 3-
factor, or uni-dimensional model best fitted the data using confirmatory factor analysis. This study concluded that the 5-factor model consistently emerged, regardless of the statistical analysis employed, presenting a strong argument that the five domains of growth contained within the PTGI accurately measure the phenomenon of posttraumatic growth.

3.2. Posttraumatic Growth as an Illusion

The theories by Janoff-Bulman and Tedeschi and Calhoun are key examples of theories that view growth as an outcome, or something constructed from the process of changing core beliefs. An alternate theoretical position is that posttraumatic growth reflects an illusory coping mechanism. It is generally accepted in the literature that the key distinction between theories that posit growth as a construction and growth as an illusion is the veridical nature of growth. Specifically, theories that view posttraumatic growth as an outcome (e.g. Janoff-Bulman and Tedeschi and Calhoun) are thought to reflect real, measurable, objective change in the individual from pre and post trauma states (Park, 2009). In contrast, theories that view growth as an illusion propose that growth simply represents people’s perception of change as a way to cope with the stressor and, as such, growth is a by-product of coping that may or may not reflect actual change (Park, 2009). One key way that the illusion of growth is created is through cognitive coping mechanisms that focus on positive appraisals of the situation (Zoellner & Maercker, 2006).

3.2.1 Taylor’s Theory of Cognitive Adaptation.

Taylor (1983) proposes that, when an individual is faced with a threatening event, such as a diagnosis of cancer, they commence a re-adjustment process. This process involves three components: (a) the search for meaning; (b) attempts at mastery (of the situation and of life in general); and (c) attempts at self-enhancement (Taylor, 1983). Importantly, in this foundational study of breast cancer patients and their spouses, Taylor (1983) found evidence that both patients and their spouses engage in the search for meaning and efforts to gain a sense of mastery; however, spouses do so to a lesser extent than the patients themselves. This finding has crucial
implications for the present studies, as it has demonstrated the presence of similar responses with both the cancer patient and a significant other.

The search for meaning involves two key components: firstly, a causal aspect that includes a search to understand why the event has occurred, and secondly, an understanding of the significance of the event, and an acknowledgement of the impact that it has on one's life (Taylor, 1983; Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000). This component in the adaptation process is comparable to the suggestion by Janoff-Bulman and Frantz (1997) that individuals search for both a meaning of comprehension and a meaning of significance. In the foundational study, Taylor (1983) found that typically causal attributions related to genetics/heredity, past events such as medication use, exposure to environmental carcinogens, previous stressful events, or aspects relating to health, such as diet and exercise. Searching for meaning that examined the significance of the disease allowed individuals to reappraise their lives, change their perspectives and priorities, increase their self-knowledge and allocate more time to the relationships that were of key importance. It is clearly evident that the search for meaning in the theory of cognitive adaptation (Taylor, 1983) is parallel to several domains of posttraumatic growth suggested by Tedeschi and Calhoun (2004), specifically an enhanced appreciation for life and the new possibilities it contains, increased closeness in personal relationships, and recognition of one’s strengths. This search for meaning also closely reflects the third model of growth proposed by Janoff-Bulman (2004), existential re-evaluation.

The second process of cognitive adaptation involves the individual’s attempts to gain a sense of mastery. This component of the theory was found to be largely influenced by the individual’s beliefs relating to personal control, specifically the ideas that they had relating to how they could prevent a repetition of the event, in this case a recurrence of cancer (Taylor, 1983). Adjustment was linked to the notion that direct control over cancer was possible, either by oneself or medical professionals. Additionally, the cancer patients suggested that one could prevent a recurrence through adopting a positive attitude towards life, using techniques such as
meditation and self-hypnosis, through educating oneself about cancer to enable knowledgeable decision making regarding one’s care, and through the modification of health behaviours, such as diet and eliminating medication use (Taylor, 1983).

The concept of perceived control has been demonstrated to be an important factor in optimal psychological adjustment in many diseases, including cancer, rheumatoid arthritis, cardiac disease, HIV/AIDS, multiple sclerosis and spinal cord injury (see Thompson and Kyle, 2000, for review). In a further examination of the relationship between the concept of control/mastery and adjustment to cancer, Taylor, Lichtman, and Wood (1984) analysed interview data obtained by breast cancer patients to conclude that perceptions of both personal control and vicarious control (i.e., that others could control the cancer) were related to positive psychological adjustment. It was found that the two forms of control most strongly associated with positive adjustment were cognitive control (e.g., control through attitude change) and behavioural control (e.g., increased exercise, increased leisure time).

Stiegelis et al. (2003) conducted a longitudinal study that compared cancer patients and matched control subjects on the dimensions of Taylor’s theory of cognitive adaptation. This study examined the participants’ control beliefs pre-treatment (radiotherapy), shortly post-treatment (2 weeks after), and 3 months after treatment. While there were no differences in perceived control between the cancer patients and control participants, Stiegelis et al. (2003) found that, when control was examined in relation to emotional adjustment, low control beliefs were predictive of self-reported anxiety levels and depressive symptoms 3 months post-treatment. This finding indicates that control may play a vital role in overall emotional adjustment to the cancer experience, and that positive adjustment appears to be related to higher levels of perceived control. Similar findings have been suggested by Taylor, Helgeson, Reed, and Skokan (1991) in relation to coronary heart disease and AIDS patients. Specifically, for cardiac patients, control was found to reduce anxiety and depression, while high perceptions of personal
control in AIDS patients was strongly associated with positive psychological adjustment (Taylor et al., 1991).

The final aspect of the theory of cognitive adaptation is self-enhancement (often used synonymously with self-esteem), which Taylor (1983) suggests is largely achieved through the upward and downward comparison of oneself to others. Firstly, in explanation of the upward comparison to self, the women interviewed post-treatment by Taylor indicated that they believed they were not only better adjusted than they were during their treatment, they were also better adjusted then they were before their cancer diagnosis. Therefore, using their past selves as comparison yard sticks, the women believed that going through the cancer experience had improved their overall psychological adjustment.

A second strategy of self-enhancement that was evident was downward comparison to their peers. The majority of the cancer patients suggested that they were coping as well or better than other women they knew going through the same experience (e.g., luckily I only had a lumpectomy, not like poor Sue who had a mastectomy). If a concrete example was not available, some women manufactured a hypothetical norm with which to compare themselves (e.g., I am not doing too badly, imagine how dreadful this would be if I was not married; Taylor, 1983). Taylor (1983) suggests that this process is an attempt to validate the individual’s favourable self-image by casting her as someone who is facing a terrible threat, yet taking it all in her stride.

Taylor (1983) proposed that the processes involved in the cognitive restructuring required for adaptation (i.e., establishing meaning, gaining control and self-enhancement) are intricately linked with ‘positive illusions’. Indeed, the presence of positive illusions allows for selective focus and evaluation, leading to a favourable reinterpretation which allows the individual to find the positive aspects out of a negative situation (Taylor & Updegraff, 2000). Specifically, it is argued that the cognitions, which are used as the foundation for the individual’s adaptation, may have no factual basis (Taylor, 1983; Taylor & Brown, 1988). For example, a cancer patient
may believe that they can control their cancer and prevent its return by engaging in twenty minutes of meditation daily. While there is no proof that such an activity will prevent cancer, the belief contributes to the patient’s adaptive responses to their disease, and as such contributes to their overall adjustment and acceptance of their situation. Taylor (1983) and her colleagues (Taylor & Armor, 1996; Taylor & Brown 1988) argue that illusions should not be viewed as a sign of psychological maladjustment, but rather that illusions may be beneficial in that they may contribute to healthy, rather than poor, adjustment. Furthermore, engaging in mildly positive perceptions of self and control (the search for meaning may be viewed as a form of interpretive control; Taylor, 1983), accompanied by an overly optimistic outlook concerning one’s future (Taylor & Brown, 1988), may facilitate an individual’s return to healthy psychological functioning by providing an adaptable, self-protective and functional set of beliefs that enable the individual to deal with stressful events as they arise (Taylor, 1983; Taylor & Armor, 1996). Indeed, Taylor (1983) suggests that the illusions of control, self-esteem and optimism may serve more than one function; they may protect the individual, whilst bringing forth constructive thought and action.

While the suggestion that positive psychological adjustment is associated with illusion has generated considerable debate (see Colvin & Block, 1994; Taylor & Brown, 1994), Taylor has maintained that illusion is crucial for adaptation to threatening events and that, furthermore, illusion does not equate to the complete absence of reality. Indeed, Taylor, Kemeny, Reed, and Aspinwall (1991) argue that “illusion may need to operate within realistic boundaries or constraints to be adaptive” (p. 251). For example, it has been demonstrated that the influence of perceived vicarious control on adjustment is associated with disease prognosis (Taylor, Helgeson, Reed, & Skokan, 1991), in that holding firm beliefs that doctors can cure one’s disease in the face of a poor prognosis is linked to poor adjustment to one’s situation. Taylor, Kemeny, Reed, and Aspinwall argue that the reason why vicarious control is linked to maladjustment in cases with poor prognosis is that there realistically is very little that others can do to overcome the disease, and holding such beliefs represents a maladaptive perception.
Overall, Taylor, Kemeny, Reed, and Aspinwall (1991) argue that positive illusions that are balanced with reality allow the maintenance of the individual’s integrity, and therefore allow positive adaptation to occur.

3.3. Current Debates in the Posttraumatic Growth Literature

Historically, the notion of finding something good in a negative situation is embedded in numerous cultures and philosophies (e.g., Ancient Hebrews and Greeks), and is present in literature and the dramatic arts (Tedeschi & Calhoun, 1995). Despite this, the systematic study of growth from trauma is relatively new in the field of psychology (approximately 30 years; Tedeschi & Calhoun, 2004). The focus on the concept has been increasing, as the discipline shifts its focus from disorder to human strength, due to the movement towards positive psychology (Seligman & Csikszentmihalyi, 2000). As a result, there has been a sharp increase in studies that have examined the concept of posttraumatic growth in a wide variety of stressful situations, with some authors now proposing interventions to assist in the development of growth in clinical settings. Such a contention that growth should be encouraged and developed may, however, be unwarranted with a growing number of voices (e.g., Coyne & Tennen, 2010; Sumalla et al., 2009; Zoellner & Maercker, 2006) arguing that the concept is still in its infancy, and much more research needs to be conducted before clinicians start utilising the concept. Zoellner and Maercker (2006) summarise the current standing of the field, when they state that posttraumatic growth is “not well-understood and cannot yet be described in a theoretically satisfying manner or measured with reliability and validity” (p. 649). The following sections briefly outline some of the current debates within the field, highlighting the unknown aspects of the concept, and arguing for the need of greater clarification of the core construct.

3.3.1. Conceptual ambiguity and confusion between terms.

As outlined above, there are two distinct schools of thought regarding whether growth is a constructed or illusory phenomenon. However, that debate is but one sign of the greater conceptual ambiguity underpinning the concept of posttraumatic growth. The position that growth
is a constructed phenomenon, which brings about change, argues that the change is beneficial and occurs within our basic beliefs and assumptions. Models that emphasise growth as an illusory process highlight the functional nature of growth, namely to reduce the distress brought forth by the extreme event through the distortion of self-appraisals (Sumalla et al., 2009). Additionally, Zoellner and Maercker (2006) argue that there may be another way to conceptualise post-traumatic growth in a model that combines both perspectives.

Under the Janus Face model proposed by Zoellner and Maercker, (2006; Maercker & Zoellner, 2004) growth is proposed to have a constructive functional side (as proposed by Calhoun and Tedeschi, 1999; Tedeschi & Calhoun, 2004), along with an illusory side (which may be perceived as being dysfunctional or deceptive). It is argued that the Janus Face model recognises that, especially in the early stages of trauma, positive illusions may serve as a protective factor that helps to offset emotional distress (Zoellner & Maercker, 2006). It is noted that the illusory side may coexist with maladaptive cognitions, such as denial, and if the illusory side is maintained long-term, it may itself constitute a maladaptive approach to recovery from trauma, as it may lead to repression (Maercker & Zoellner, 2004). If however, the illusory side is accompanied by the deliberate cognitive processes required for growth, and allows for the undertaking of active coping mechanisms, then the illusory aspect of posttraumatic growth may be a useful short-term coping response to deal with the acute impact of trauma (Zoellner & Maercker, 2006). The functional, long-term constructive aspect of growth develops over time, and largely reflects the outcomes proposed by Tedeschi and Calhoun (2004).

A strength of conceptualising posttraumatic growth as a dual process concept is that it may go some way to explaining the differential results of cross-sectional and longitudinal studies of growth in relation to well-being and distress. Although discussed in greater detail in Section 3.3.2, the general trend in findings is that cross-sectional studies show no or limited relationship between posttraumatic growth and well-being and/or distress, while longitudinal studies suggest that growth increases over time and does
influence psychological outcomes (Sumalla et al., 2009). It may, therefore, be argued that the narrow snapshot of experience, which is captured through cross-sectional studies, fails to yield positive results, because they are assessing people at various stages of the growth process, and this clouds the relationship between growth and adjustment variables.

In addition to the broad theoretical debate, there is also much disagreement amongst theorists and researchers in regard to the terminology of growth. Terms that are frequently used in the literature include stress-related growth (Park, Cohen, & Murch, 1996), adversarial growth (Linley & Joseph, 2004), posttraumatic growth (Tedeschi & Calhoun, 1995, 2004), benefit finding (Affleck & Tennen, 1996), thriving (O’Leary, Alday, & Ickovics, 1998), and sense or meaning making (Davis, Nolen-Hoeksema, & Larson, 1998). Confusing the matter further, the terms are often used synonymously, so that readers new to the topic may be forgiven for assuming writers are all referring to the same concept. However, this situation has arisen partly due to the conceptual ambiguity outlined above, and the failure by writers to clearly differentiate terms.

As seen from the empirical review of cancer literature conducted in Chapter 2, the concept of benefit finding has been elected as the focus of this thesis. While there is no denying that benefit finding sits within the broader field of posttraumatic growth, there are some subtle distinctions that differentiate benefit finding. As outlined in Section 2.3, benefit finding may be defined as “assigning positive value or significance to the event … learning about one’s strength in the face of adversity, or gaining insight into the meaning of life or the importance of relationships …” (Davis, Nolen-Hoeksema, & Larson, 1998, p. 562). Affleck and Tennen (1996) argue that benefit finding represents beliefs about the positive outcomes arising from adversity, and that it is distinct from benefit reminding, which is a coping strategy that involves engaging in deliberate cognitive reminders of one’s positive outcomes. Lechner et al. (2003) defined benefit finding as a “sense that personal growth resulted from a challenging life experience” (p. 492). As such, benefit finding represents one possible outcome of growth, it is the end product where individuals can look back on an event, and reflect on the
good things that have arisen from it. This distinction is somewhat difficult to make in the light of the fact that some theorists argue that posttraumatic growth is a process and an outcome (e.g., Zoellner & Maercker, 2006), however at no time has benefit finding been described as a process. Furthermore, benefit finding is not the central goal of posttraumatic growth, but rather one possible outcome that may arise. Essentially, posttraumatic growth represents cognitive processes and changes that give rise to the establishment of new cognitive ‘handbooks’ (or assumptions) for living. In short, posttraumatic growth is the reconstruction or strengthening of perceptions relating to self, others and events (Mols, Vingerhoets, Coebergh, and van de Poll-Franse, 2009). However, posttraumatic growth may also lead to overt behavioural changes, with Tedeschi, Calhoun and Cann (2007) arguing that posttraumatic growth “involves internal changes that can set the stage for changed behaviour” (p. 399). Benefit finding can be viewed as positive, measurable by-products of the growth process, whilst the occurrence of growth itself is evident by changes in the underlying schemas that people live by, and/or their behaviours. These changes are frequently expressed as perceived benefits. We can therefore consider posttraumatic growth as the process of change that gives rise to benefit finding, however benefit finding may occur, regardless of whether actual posttraumatic growth has occurred (Park, 2009). For instance, it is possible, that in response to having a spouse diagnosed with melanoma, the healthy partner will change their health behaviours to include greater use of sunscreen and wearing a hat. These changes reflect benefit finding, and may have occurred without any significant struggle with or cognitive processing of the cancer experience (i.e., without posttraumatic growth). Indeed, such changes may be viewed as the beneficial, yet natural consequences, of the experience of having a spouse diagnosed with melanoma.

3.3.2. Relationship between posttraumatic growth and psychological adjustment.

Intuitively, it seems that posttraumatic growth would be linked to psychological outcomes arising from trauma. If given a brief description of posttraumatic growth and benefit finding, the lay person might conclude that, if an individual was able to find benefit from their experience, they
would report higher levels of well-being and lower levels of distress. After all they have managed to find a ‘silver lining’ in the traumatic experience. However, research has failed to find a consistent relationship between benefit finding/posttraumatic growth and psychological outcomes, leading Sumalla et al. (2009) to conclude that “we do not as yet have sufficient empirical evidence to confirm the association between posttraumatic growth and the lack of distress and/or psychological well-being (p. 30). Similar sentiments are espoused by Coyne and Tennen (2010) and Zoellner and Maercker (2006), with both parties arguing for the need for improved research designs and a greater focus on conceptual refinement.

Looking specifically at the research, it is easy to find contradictory findings. For example, within the research on breast cancer patients, Tomich and Helgeson (2006) found that benefit finding was associated with greater negative affect and poorer mental functioning. On the other hand, Carver and Antoni (2004) reported enhanced positive emotions, lower depression, and better life conditions. Finally, Helgeson, Snyder, and Seltman (2004) found that benefit finding did not have any impact on overall adaptation to breast cancer. Similar conflicting findings are evident in anxiety research. For example, Dunn et al. (2011) found anxiety to be unrelated to benefit finding in a sample of cancer patients, while Loiselle et al. (2011) found a significant negative correlation between posttraumatic growth and trait anxiety in a sample of relatives dealing with a serious illness, such as cancer, diabetes, and pulmonary disease in a family member.

There are several possible explanations for the failure of a great volume of research to find a systematic relationship between posttraumatic growth and psychological adjustment. One possible explanation arises from the theoretical underpinnings of growth. Specifically, posttraumatic growth represents a shift in a person’s core assumptions from believing the world is safe and just to recognising that life is uncertain and that there is always the risk of personal harm. It may therefore be argued that successful growth, in the form of altered schemas, may actually represent a more negative view of the world, and therefore growth would not be linked to improved well-being (Park, 2009).
A second reason may be related to research design, with longitudinal research tending to more consistently find a relationship between such variables. Specifically, in relation to depression, Zoellner and Maercker (2006) concluded in their review that cross-sectional studies typically reported null findings between posttraumatic growth and depression. However, a longitudinal study by Frazier et al. (2001) did find that individuals, who reported an increase in posttraumatic growth over a 12-month period, reported lower levels of depression when tested at Time 2. A similar pattern emerges for symptoms of PTSD with cross-sectional studies reporting null results, and longitudinal studies suggesting that growth is linked to lower symptom levels (Zoellner & Maercker, 2006). Such findings support the concept of the Janus Faced model of growth, suggesting that the process of growth may increase over time, and so may demonstrate a different pattern of relationship to adjustment variables at various points throughout the process, differences that are unable to be assessed through cross-sectional designs.

Finally, a third explanation is that there are other circumstances or variables that influence the growth-adjustment relationship. Coyne and Tennen (2010) argue that the relationship between growth and adjustment may be curvilinear, or that moderator variables may be at play. However, to date it is unknown what such moderator variables are. McMillen (1999, 2004) has written critically on growth theories and their inability to incorporate non-cognitive features. He argues that theories of growth and adaptation, which focus largely on cognitions, are in danger of losing sight of the bigger picture, that people live in a larger environment than simply their mind and its workings. It is McMillen’s opinion that growth models should consider the factors of culture, self-efficacy, social comparison, social support, religiosity, the severity of an event, socio-economic status, optimism, pre-adversity functioning and coping capacity. Whilst McMillen himself does not propose a growth theory, the value of the variables he suggests is evident, as they include aspects of both pre- and post adversity functioning, and acknowledge the role that the social context may play in influencing growth.
In support of the assertions by McMillen (2004) and Coyne and Tennen (2010), a large number of researchers have argued for a more comprehensive view of posttraumatic growth. Linley and Joseph (2004) conducted a review of empirical studies that investigated trauma-related growth to determine the variables that have shown an empirical association with stress-related growth. In a review of 39 studies, they concluded that a multitude of variables have demonstrated relationships with the posttraumatic growth phenomena, including variables related to the stressful event, cognitive processes, socio-demographic aspects, personality, coping, social support, religion, affect, quality of life, distress and time (see Linley & Joseph, 2004 for a comprehensive summary). Specifically, Linley and Joseph found support for some of the variables suggested in the theories outlined above (e.g., positive associations of growth with controllability and rumination). However, they also suggested that other variables (e.g., positive affect, satisfaction with social support and duration since event) play a significant role in the development of posttraumatic growth. The role of resilience in relation to posttraumatic growth is also debated, with some suggestion that growth may be a form of resilience (Lepore & Revenson, 2006; Nishi, Matsuoka, & Kim, 2010); that posttraumatic growth may lead to increased resilience (Banyard & Cantor, 2004), while others argue that the two are unrelated responses to trauma. It has been argued that individuals high in resilience may report no or low levels of posttraumatic growth, as the traumatic stressor is not perceived as overly challenging (i.e., they are able to cope successfully due to their resilience, and therefore do not need to engage in cognitive activity to alter psychological assumptions), therefore the possibility of growth is greatly reduced (Levine, Laufer, Stein, Hamama-Raz, & Solomon, 2009; Tedeschi & Calhoun, 2004; Westphal & Bonanno, 2007). Zoellner and Maercker (2006) highlight that various personality features, such as hardiness, sense of coherence, and optimism, may be influential in growth development, whilst Stanton and Low (2004) argue for a greater consideration of positive emotions in models of growth. Prati and Pietrantoni (2009) reviewed 103 articles on posttraumatic growth and concluded that optimism and social support were moderately related to posttraumatic growth, and therefore may warrant inclusion in any theory on
the area. Additionally, Park (2004) argues that, to be comprehensive, models of growth need to consider both the positive and negative changes (i.e., benefits and losses) that arise from a stressful event, as such an examination may assist in determining the roles of the variables and the extent to which they contribute to overall psychological adjustment. From such arguments, it may be concluded that researchers should be mindful of the possible influence of other variables on growth, and ensure that future research helps to clarify whether moderating or mediating effects are occurring.

3.3.3. Problems with measuring posttraumatic growth and benefit finding.

The final area of debate within the literature pertains to the measurement of posttraumatic growth and benefit finding. Since the 1990’s there have been a number of posttraumatic growth and benefit finding measures that have emerged in the psychological literature. Scales such as the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996), Benefit Finding Scale (Antoni et al., 2001; Tomich & Helgeson, 2004), Perceived Benefits Scale (McMillen & Fisher, 1998), Changes in Outlook Questionnaire (Joseph, Williams & Yule, 1993), Stress Related Growth Scale (Park, Cohen & Murch, 1996), Life Change Measure (Frazier, Conlon & Glaser, 2001), and the Thriving Scale (Abraido-Lanza, Guier, & Colon, 1998) have been developed, however the quality of the available psychometric information relating to each scale’s structure and validity is often less than desirable. For example, the 17 item Benefit Finding Scale (Antoni et al., 2001; Tomich & Helgeson, 2004) has started to be used increasingly in research; however details regarding the scale’s structure and availability validity information is scant. For example, the original developers (Antoni et al., 2001) did not perform any analysis to determine scale structure, and only provided validity information regarding the scale’s relationship with optimism, distress, positive emotions, and concerns about breast cancer. As such, there is no component structure available for the measure, and the validity of the scale in relation to other theoretically similar measures has not been tested.
Subsequently, the scale structure is debated, with researchers who have performed component analysis on the scale finding two (Tomich & Helgeson, 2004), or four component (Urcuyo, Boyers, Carver, & Antoni, 2005); however, in both studies the researcher’s proposed that a unitary factor structure was more appropriate for reasons such as scree plots, correlations between factors, and high factor cross loadings. More recent research conducted by Weaver et al. (2008) examined the factor structure of a revised 29-item version, with no explanation of how the additional items were developed, and with the factor structure suggesting a multi-dimensional model of benefit finding containing six factors. In their brief summary of available measures, Zoellner and Maercker (2006) argue that, despite a growing number of scales purporting to measure posttraumatic growth and benefit finding, to date, the only two standardised and validated measures are the PTGI (Tedeschi & Calhoun, 1996) and the Stress Related Growth Scale (Park, Cohen, & Murch, 1996).

A second issue regarding self-report growth and benefit finding measures is whether such scales over or under represent positive change. Nolen-Hoeksema and Davis (2004) point out that studies using self-report scales typically find that the majority of their participants report some form of benefit, with most participants reporting high numbers of positive outcomes. In contrast, studies, which use open ended questions to explore positive outcomes, find that 20-50% of the sample do not report beneficial change (Nolen-Hoeksema & Davis, 2004). Such a finding suggests that self-report scales may over-estimate the prevalence and magnitude of benefit finding. However, in contrast to Nolen-Hoeksema and Davis, research performed by S. G. Smith and Cook (2004) suggest the opposite may occur, and that indeed current measurement methods may lead to an under-estimation of growth. Specifically, S. G. Smith and Cook argue that the current practice of linking growth and benefit finding measures to a specific traumatic incident (e.g., cancer, sexual assault) may actually lead to an under-reporting of growth outcomes. The study by S. G. Smith and Cook examined difference in reported growth in two groups, one group was directed to consider their growth in light of a specific stressful event (i.e., the most challenging event that has occurred to you within the past four
years), while the second group was directed to consider the past four years generally. S. G. Smith and Cook found that there was a small but significant difference in the level of growth reported, particularly in the areas of personal strength and relating to others in the group directed to link their growth to a specific event. S. G. Smith and Cook concluded that asking participants to reflect upon the impact of a specific event may lead them to be overly cautious in attributing their growth to the event, and hence report a lower level of growth.

Coyne and Tennen (2010) have written critically on self-report scales for growth and benefit finding, arguing that the task required to complete such scales is multi-faceted, and therefore people are unlikely to accurately portray their level of growth. Specifically, it is argued that self-report scales require participants to evaluate their current functioning, recall their functioning prior to the event, compare the two, decide on the degree of change, and then determine how much of that change is attributable to the stressful event (Coyne & Tennen, 2010). Coyne and Tennen argue that research that has compared perceived and actual change over time in the areas of personality and personal relationships typically finds that there is a non-significant or modest relationship between perceived and actual change. In light of this, Coyne and Tennen conclude that people cannot recall personal change accurately, and therefore the task required by posttraumatic and benefit finding measures is too complex for accurate representation of actual change. In response to this criticism, Aspinwall and Tedeschi (2010) argue that Coyne and Tennen should not compare research investigating change in personality and relationships with research investigating change due to trauma. Specifically, Aspinwall and Tedeschi suggest that traumatic events are so disruptive to the individual’s life that they serve as “markers that divide the life narrative into before and after the event” (p. 31). This clear delineation of life into pre and post trauma may therefore make it easier for people to compare their old life to the “new normal” (Aspinwall & Tedeschi, 2010, p. 31) that has emerged.

The final measurement issue relates to whether scales that claim to measure posttraumatic growth and benefit finding measure actual growth
and positive change, or rather the individual’s perception of growth/change. Park (2009) argues that the measurement of growth, as it is currently practiced, does not represent actual growth, but rather self-perceived positive change, and as such may be influenced through self-distortions and other cognitive biases. Similar sentiments are echoed by Stanton and Low (2004), who call for the increased use of behavioural and interpersonal assessments to improve the validity of assessments of posttraumatic growth. Recent research by Frazier et al. (2009) attempted to address the issue of perceived versus actual growth, by having their sample complete the PTGI as a measure of perceived growth, and additional, widely used and validated measures that reflect actual growth in the five domains of the PTGI. Frazier et al. found that perceived growth (i.e. scores on the domains within the PTGI) were largely uncorrelated with scores on the measures of actual growth that were used. These non-significant finding arose despite strong significant correlations between the subscales of the PTGI and the actual growth measures. From these findings, Frazier et al. concluded that the PTGI is unable to measure actual pre and post trauma change. In response to these findings, Aspinwall and Tedeschi (2010) have argued that the measures used as indicators of actual growth were also self-report measures, and therefore subject to the same methodological flaws and biases as the PTGI scores. Furthermore, they argue that the measures used as indicators of actual growth represent absolute levels of those constructs, whereas the PTGI subscales measure change in those domains, therefore Frazier et al. have essentially inappropriately compared change with absolute levels. Finally, Aspinwall and Tedeschi cite prior research by Durkin and Joseph (p. 34) that suggests the correlation between the PTGI and the measures of actual growth has been found to be low (ranging from .08-.20), and therefore the actual growth measures used by Frazier et al. should not be viewed as proxies for posttraumatic growth.

In light of the arguments presented above, there has been an increasing number of researchers who have called for greater methodological rigour in the study of posttraumatic growth and benefit finding. For example, Cohen, Hettler and Pane (1998) recommended that the validity of the concepts could only be established through the use of
prospective study designs that specifically compared pre and post trauma growth domains (actual growth) with perceived change on the same domains. Stanton and Low (2004) call for increased objectivity in the reporting of growth through the use of third-party reports and behavioural observations. Additionally, Zoellner and Maercker (2006) call for greater use of longitudinal designs to allow researchers to examine change over several time points, and ideally pre and post trauma. Despite such calls, most research typically continues to utilise self-report scales, such as the PTGI (Tedeschi & Calhoun, 1996), in cross-sectional designs.

Taken together, the arguments above clearly identify that there are issues relating to both the conceptualisation and measurement of posttraumatic growth and benefit finding. Despite such limitations, the area remains a field of great potential in understanding human strength that may, in the long run, yield fruitful therapeutic insights. In an effort to expand our understanding of benefit finding, the chapter now turns to the aims of the first study conducted within this thesis.

3.4 Study One Research Aims

In the light of the empirical and theoretical material reviewed in Chapters 2 and 3, it is clear that there is much that remains unknown in the area of posttraumatic growth, especially as it relates to the adult children of cancer patients. Much of the existing research has focused on psychopathology, largely ignoring the possibility that positive psychological growth may occur within this cohort. To address this limitation, a series of two studies was planned as the basis of this thesis. Specifically, a qualitative semi-structured interview study was planned to investigate the phenomenon of benefit finding in adult children of cancer patients. Depending on the findings of the qualitative study, a second, larger quantitative survey study was planned, with the intention of confirming the key results and further investigating the relationships between key variables identified in Study One.

The empirical data strongly suggests that benefit finding is possible in the spouses of cancer patients, and there is emerging evidence to suggest
that the adult children of cancer patients might report similar benefits. As such, the aims of Study One were to:

1. Investigate the extent of perceived benefit finding in adult children of cancer patients;
2. Investigate the types of benefits that adult children report, assessing how they fit within the classification of benefits described by Tedeschi and Calhoun (1995) and Thornton (2002);
3. Examine the data to ascertain if one particular theoretical model (i.e., growth as construct, growth as illusion, growth as a dual component model) seemed to emerge from the descriptions of the experience of parental cancer.
Chapter 4: Study One Methodology

The current chapter proposes a rationale for Study One, arguing the need to adopt a qualitative methodology, namely a semi-structured interview study using an interpretive phenomenological analysis. The philosophical foundations of the interpretive phenomenological analysis approach are outlined, examining the phenomenological and symbolic interactionism schools of thought. The chapter then details the steps taken in the research process to enhance the methodological rigour of Study One. The final sections of the chapter then examine the method employed, describing the study participants, interview development, data collection and data analysis phases.

After consideration of the lack of research into the topic of benefit finding in parental cancer and the research aims, it was decided that Study One would employ a qualitative methodology. Silverman (2006) argues that it is crucial to select a research method that complements what the researcher is trying to discover. As the current study can be considered largely exploratory, a qualitative approach is ideally suited, as such methods allow for the collection of rich and detailed data that can help guide future research projects (Bryman, 1988). Furthermore, the value of qualitative methods is evident as it allows the research to discover the meaning of the topic for the participants (Denscombe, 2003), without the imposition of operational definitions that may contradict people’s beliefs and experiences (Silverman, 2006).

4.1 Philosophical Foundations

J. A. Smith’s (1996, J. A. Smith, Flowers & Osborn, 1997; J. A. Smith & Osborne, 2003) methodological view for interpretive phenomenological research served as the guiding framework and methodological approach for examining the experience of parental cancer. The interpretive phenomenological approach has been utilised within the field of health psychology to investigate a range of phenomena (e.g., lower back pain, practitioners views of working with patients with anorexia, sexuality and HIV positive men), and it is argued that interpretive
phenomenology provides a suitable avenue for exploring illness, the body, and people’s views on their health (J. A. Smith, Jarman & Osborn, 1999). Interpretive phenomenology has its theoretical underpinnings in phenomenology and symbolic interactionism, and each of these philosophical foundations will be briefly outlined.

Phenomenology is a philosophy that is concerned with exploring the lived experience of humans (van Manen, 1997), examining the world as it is perceived by people, and gaining insight into how people gain knowledge from the world (Willig, 2001). The rise of phenomenology is seen as a reaction to purely empirical studies of human experience and behaviour, which were seen as occurring through psychology’s attempt to apply the principles of natural science to humans (Laverty, 2003; Moran, 2000). Husserl (1913/1969), the philosopher credited with the shifting the focus of philosophy to phenomenology, argued that the application of natural science principles to human experience reduced humans to subjects who react automatically to external stimuli, and that humans were far more complex than that. Rather, Husserl argued that the focus of study needed to be “trying to understand or comprehend meanings of human existence as it is lived” (Laverty, 2003, p. 4).

Under a phenomenological perspective, the study of consciousness is essential, as the ultimate goal of phenomenological inquiry is to “describe phenomena, in the broadest sense as whatever appears in the manner in which it appears, that is as it manifests itself to consciousness, to the experiencer” (Moran, 2000, p. 4). As such, the content of consciousness is the subject of study, with Husserl proposing that consciousness is the co-constituted dialogue between the person and environment (Valle, King & Halling, 1989). Husserl viewed consciousness as intentional in that it is always directed towards, or grasping some phenomenon (Stewart & Mickunas, 1990). Self-reflection on events, objects and concepts was seen as the basis of knowledge, leading to a comprehensive description of the content of ordinary life.
Groenewald (2004) emphasises that the key to phenomenology is the description of phenomena, as it is through accurate description that insight into lived experiences is gained. Achieving an accurate description requires three phases: epoche, phenomenological reduction and imaginative variation (Moustakas, 1994; Willig, 2001). Epoche is the critical phase, a suspending of all previously held preconceptions, assumptions, judgements and beliefs to ensure that the person is open to the experience as it is lived. When epoche is achieved, the individual can view the experience afresh, without interference from biases and, as such, contact with the essence of the experience is possible (Ashworth, 1996; Laverty, 2003; Polkinghorne, 1989). Husserl proposes that epoche is accomplished through the process of bracketing, which involves acknowledging and eliminating pre-existing thoughts relating to the phenomenon (Ashworth, 1996). In phenomenological reduction, the description of the phenomenon occurs, with attention directed to the physical (e.g., texture, colour) and experiential (e.g., thoughts, feelings) features of the experience (Willig, 2001). Finally, imaginative variation involves consideration of how the phenomenon is possible, with the aim being to gain insight into the conditions that give rise to the phenomenon (Moustakas, 1994; Willig, 2001).

Heidegger argued that Husserl’s requirement of the suspension of researcher presuppositions in epoche was unachievable, arguing that “an interpretation is never a presuppositionless apprehending of something presented to us” (Heidegger, 1962/1978, p. 191). Instead, Heidegger proposed a hermeneutic phenomenology that acknowledges the role of the researcher’s views on understanding the experience. It was Heidegger’s view that people and the world are inextricably linked through cultural, social and historical contexts (pre-understanding and historicality; Munhall, 1989; Laverty, 2003). This pre-understanding is unable to be ‘turned off,’ and so Heidegger argued that nothing can be experienced without some reference to a person’s background understanding, and that indeed meaning was constructed through the interaction of background and experience (Laverty, 2003).
Overall, the philosophical school of phenomenology claims to adopt a scientific approach to research, arguing that it is systematic, explicit, and self-critical (van Manen, 1997). The approach is systematic as it employs specific styles of questioning (e.g., what did you experience? what was that like for you?), focusing, reflecting (e.g., bracketing, memoing), and drawing meaning (Groenewald, 2004; Polkinghorne, 1989; van Manen, 1997). Phenomenological research is explicit as it aims to articulate the meaning of lived experience. Essentially, the research is intended to determine what an experience means to the people who live through it, and then provide a comprehensive description of that experience (Moustakas, 1994). Finally, phenomenological studies are self-critical, in that a reflection of goals and methods to identify limitations and strengths is incorporated into the research process (van Manen, 1997).

The second philosophical school of thought underpinning the interpretative phenomenological approach is symbolic interactionism. The symbolic interactionism movement was founded within sociology in the United States, with the founding fathers of Cooley, Mead, and Blumer (Travers, 2001). The aim of social interactionism is to understand the lived experience of people through an examination of interactions both within an individual (i.e., their thoughts and interpretations), and between individuals and groups (Denzin, 1995; Ephross & Greene, 1991). It is also acknowledged that most interactions occur through primarily the use of language, and to a lesser degree other symbols (e.g., gestures, facial expressions, tone of voice; Ephross & Greene, 1991).

Social interactionism rejects the search for global theories and infinite truths, instead arguing that the individual story and the “situated versions” (Denzin, 1995, p. 44) of events and societies are more suitable avenues of investigation. The focus is on social interaction, defined as the “reciprocal influence of individuals” (Ephross & Greene, 1991, p. 208). This definition recognises that individuals experience the world through dynamic social processes, and such processes have the potential to change individuals and their understanding of their world (Charom, 1995). However, symbolic interactionism does not view the individual as a passive
vessel into which meaning and symbolism is poured by others. Rather, the individual is viewed as an active constructor of meaning; an object or event itself has no meaning until the individual infers meaning upon it through a process of active intervention, interpretation and definition, according to the object or event’s relevance and/or use to the individual (Charom, 1995; Ephross and Greene, 1991). In this manner, “individuals are influenced by other people, but they are also active in interpreting and responding to the people and objects that they encounter in the world” (Travers, 2001).

Blumer (1969) argued that meanings determine the experience of a person, and are the central force in shaping human behaviour. Indeed, Blumer argued that “to bypass the meaning in favour of factors alleged to produce the behaviour is seen as a grievous neglect of the role of meaning in the formation of behaviour” (p. 3). For example, imagine a couple walking along a beach. Person A notices the way in which the sun warms his skin, the sense of peace that he feels from observing the repetitive motion of the waves, and the comfort of sharing this experience with someone that he cares for. Through interpretation, Person A develops a meaning for the experience of walking on the beach as one that is calming and joyful, and is therefore likely to repeat the behaviour. In contrast, Person B notices the way that the wind blows her hair into her eyes, and that the sound of waves crashing makes conversation difficult. This person ascribes a meaning of annoyance and irritation to the experience of walking on the beach, and therefore is less likely to repeat the behaviour in the future.

Symbolic interactionism recognises that meaning, once developed, remains changeable, and is altered by new interpretations as the individual encounters the object or event in new social situations (Denzin, 1995). According to Charom (1995), Mead argued that everything about human life should be considered a process, rather than stable and fixed, and as such absolute truths could not exist. The goal of the researcher working within a symbolic interactionism paradigm is to capture an understanding of ‘how’ an event has been experienced (Denzin, 1995). As such, the symbolic interactionist avoids questions of why, accepting that each individual will develop their own unique understanding and meaning for the event, and
therefore broad explanations of why a thing happened are not worthwhile pursuits.

Interpretive phenomenological analysis differs from phenomenology in that it accepts that the researcher’s conceptions and beliefs are unable to be completely suspended, as pure phenomenological studies would require (Willig, 2001), and so adopts a more Heideggerian philosophy. Interpretative phenomenological analysis embraces the researcher’s preconceptions, arguing that research is a “dynamic process with an active role for the researcher” (J. A. Smith & Osborn, 2003, p. 51). This is where the symbolic interactionism foundation comes to play, with interpretative phenomenological analysis recognising the interaction between researcher and participant, both in terms of data collection, and more importantly in terms of analysing the data. Interpretative phenomenological analysis would argue that the exploration of data will always involve the researcher’s view of the world, and indeed this is required for the researcher to make sense of the data (J. A. Smith et al., 1999; Willig, 2001). Specifically, interpretative phenomenological analysis proposes that the researcher’s inescapable background knowledge and beliefs form the perceptual lens for conducting the study, the lens through which interpretation of the data occurs (Benner, 1994). The interpretative phenomenological researcher aims to “accurately present the voice of the participants . . . [but then] moves to a level of commentary that . . . should clarify the meanings of the . . . description and articulation [of the phenomena]” (Benner, 1994, p. 101). In essence, the insight gained through this methodology comes from interpretation.

The main aim of interpretative phenomenological analysis is to enhance our understanding of the world through gaining an insight into how people perceive and experience events and objects in their lives. However, interpretative phenomenological analysis goes one step further than simply getting participants to describe events; rather, interpretative phenomenological analysis aims to gain an insight into the meaning that people attribute to events and objects (Willig, 2001). The notion of exploring participants’ points of view is crucial, and researchers are encouraged to adopt an insider’s perspective as much as possible (J. A.
Smith et al., 1999). The insider’s perspective is achieved through engagement with the data, based on the assumption that the accounts, which people provide, inform us of lived experiences (Willig, 2001).

A distinguishing feature of interpretative phenomenological analysis is the method’s consideration of cognitions, and specifically with “understanding what the particular respondent thinks or believes about the topic under discussion” (J. A. Smith et al., 1999). Such a position assumes that there is a clear connection between what is verbally expressed, what is thought, and what is felt and experienced by the physical being, and that the individual does indeed possess a compilation of cognitions (ideas, beliefs, expectations etc) that they use to make sense of their experiences (Willig, 2001). This interest in cognitions is incompatible with some aspects of phenomenological philosophy; however, such a view is compatible with the cognitive paradigm that is pivotal in contemporary psychology (J. A. Smith & Osborn, 2003). As such, interpretive phenomenological analysis represents a suitable method for exploring psychological phenomena, such as benefit finding, which is theoretically linked to challenges and changes in the individual’s core beliefs.

Study One reflects the interpretative phenomenological analysis process in that it seeks information directly from adults, whose parents have cancer, in an attempt to gain an insight into their meaning of the experience, whilst simultaneously acknowledging that how the participants have made sense of their experience will be influenced by their patterns of interaction with others. Indeed, the very topic is centred on the notions of interdependence and reciprocity being central in making meaning, as the study examines how illness in an external body can impact on the life of another. Finally, the interaction between participant and researcher allowed through a semi-structured interview approach, and the data analyses undertaken, are evidence of the interpretive aspects of this methodology.

4.2 Methodological Rigour

A common criticism of qualitative approaches in psychology is that they have the potential to be subjective, lacking validity and reliability, and
as such do not possess the rigour that is present in quantitative approaches (Henwood & Pidgeon, 1992; Parker, 2004). To overcome such concerns, procedures can be worked into the research process to address the researcher’s potential biases, experiences, selective perception and theoretical predispositions. In the current study, a number of strategies were employed to maintain the methodological rigour of the research process. These strategies included the examination of author’s assumptions, the use of a research journal, an examination of negative cases, and discussing cases with a supervisor in regard to emerging themes.

Qualitative data is inevitably influenced by researchers as they actively strive to analyse and interpret what is said by participants. To address the issue of researcher subjectivity, Denscombe (2003) proposes that researchers adopt one of two approaches: (a) to consciously distance themselves from their presuppositions or (b) to acknowledge the way that researcher subjectivity may influence the research process. The first position fits within the phenomenological position argued by Husserl, and requires the researcher to “be on their guard to distance themselves from their normal, everyday beliefs and to suspend judgements on social issues for the duration of their research” (Denscombe, 2003, p. 268). In contrast, the second position requires the researcher to acknowledge how their “identity, values and beliefs play a role in the production and analysis of qualitative data, and therefore researchers should come clean about the way their research agenda has been shaped by personal experiences and social backgrounds” (Denscombe, 2003, p. 269).

For the present study, the author perceived the second view to be a more authentic approach to the study, allowing her to acknowledge the insights and biases that had developed as a result of her own experience with parental cancer. At the commencement of the research process, the author engaged in a period of self-reflection, articulating the beliefs and biases that she held in relation to the topic (see Appendix B for a summary of this reflection). Additionally, the selected method of data analysis, interpretative phenomenological analysis, does not require the suspension of researcher preconceptions and therefore methodological coherence was
maintained (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Despite this acceptance of researcher subjectivity, it is still important that the researcher be aware of the existence of preconceptions, and considers their influence on the research process. Furthermore, it was hoped that, by engaging in this reflection, the research process would provide a legitimate voice for both the participants and the researcher (Hein & Austin, 2001).

While acknowledging the role of the researcher in the process, it is also important to recognise that the researcher plays a support role, rather than being the focus of the study (Chase, 2005). At all times, the information obtained from participants needs to be the focus of the research, to stand alone and allow the voice of the participants to resonate throughout the findings of the study. To achieve this, the researcher needs to be able to take a step back to reflect on what participants have actually said, without altering the essence of their responses through the bias of the researcher’s interpretive lens. To achieve this reflexivity, a second strategy was worked into the research process, that of keeping a reflective journal (Holly, 1987; Shenton, 2004).

At all stages of the data analysis process, the author made journal entries reflecting her interaction with the text, occasions where she was uncertain of her interpretations, possible interpretive options, insight into how her presuppositions may have influenced interpretation and how such biases were minimised. Entries also included reminders of what to look for in the transcript. For example about half way through the first reading of the first transcript, the author became very aware of the expressed emotion of the participant. Until that point, the author had been reading the transcript more ‘objectively’. Being aware that an interpretive lens had shifted, the need to examine the first section of the transcript looking for how the language conveyed underlying emotion to ensure a balanced analysis was conducted, was noted in the journal (see Appendix C for selected journal extracts).

The third strategy employed to minimise researcher subjectivity was the explicit examination of negative cases. Negative cases are accounts by
participants that do not fit within the dominant sentiments expressed by other participants (Willig, 2001). The practice of identifying negative cases is encouraged by Lincoln and Guba (1985) and Silverman (2000). Negative cases highlight potential areas of difference, and so raise questions regarding the interpretation of themes. In the current study, negative cases were found on 12 occasions, and are highlighted in the following results chapter.

The final strategy to enhance methodological rigour was the discussion of cases with a research supervisor. Specifically, the first three cases were analysed independently by both the author and a supervisor, with a subsequent examination of theme similarity and a discussion of interpretive concerns. This process revealed a high degree of similarity between the author and her supervisor in terms of the emergence of themes. Specifically, while different terminology was used to describe the themes, the essential content of themes identified by both parties was very similar. In addition to discussing commonalities, the meetings also involved the discussion of points of difference in analyses when they arose, specifically examining whether such differences reflected the operation of research biases. Such a process should not be viewed as an effort to establish inter-rater reliability for the analysis, but rather as a credibility check (Elliot, Fischer, & Rennie, 1999; Willig, 2001), designed to gauge the suitability of analysis and the influence of the author’s biases (from both a personal and theoretical perspective).

According to Ballinger (2006), such strategies can be taken as evidence of “systematic and careful research conduct” (p. 241), which is viewed as an essential part of ensuring the quality of qualitative research. The strategies provided an avenue through which the author’s thoughts and assumptions were made clear and tangible, whilst also providing mechanisms to check the impact of such beliefs and biases.
4.3 Study One Method

4.3.1 Participants.

Participants were recruited for involvement in the study through one of two means: advertisement of the study through the Charles Sturt University daily electronic news posting, or through regional radio interviews with the author. Participants were eligible for inclusion if they met the following criteria: aged over 18 at the time the diagnosis was made, diagnosis of parental cancer occurred at least 12 months ago, and if bereavement had occurred, this took place at least six months prior to participation. In total, the author was contacted by 18 adults willing to volunteer; however, seven failed to meet the eligibility criteria and were excluded, leaving a final sample of 11 participants\(^6\).

The age of the participants ranged from 24 to 52 years with the mean age being 41.92 years (SD = 9.58). The majority of the participants were female (9 out of 11). In terms of religiosity, seven participants identified with a recognised religion (Catholic = 3, Anglican = 2, Church of England = 2), two identified themselves as spiritual, while 3 identified themselves as having no religious affiliation. In terms of which parent was diagnosed with cancer, 50% of cases dealt with the mother, 33% with the father, and 17% where both parents were diagnosed with cancer. A range of cancers were present within the sample, including breast (n = 3), prostate (n = 2), multiple myeloma (n = 1), bowel (n = 1), brain (n = 1), melanoma (n = 1), pancreatic (n = 1), ovarian (n = 1), chordoma (n = 1), and lymphocytic leukaemia (n = 1). A profile of each participant and the pseudonym assigned to them is outlined in Table 4.1.

4.3.2 Interview development.

The principal technique for data collection in Study One was the semi-structured interview. Semi-structured interviewing is widely used in qualitative research, due to its flexibility and the likelihood of obtaining detailed answers rich in description (Bryman, 2004). This approach requires

\(^6\) It is suggested by Smith and Osborn (2003) that five to six participants be considered an adequate sample size in studies utilising interpretative phenomenological analysis. As this number had been exceeded from initial recruitment activities, no steps were taken to recruit additional participants.
Table 4.1

Study One Participant Profile

<table>
<thead>
<tr>
<th>Participant ID</th>
<th>Sick Parent</th>
<th>Type of Cancer</th>
<th>Outcome of Cancer</th>
<th>Time Elapsed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beth</td>
<td>Father</td>
<td>Lymphocytic leukaemia</td>
<td>Treatment ongoing</td>
<td>Treatment ongoing</td>
</tr>
<tr>
<td>Cathy</td>
<td>Father</td>
<td>Brain</td>
<td>Deceased</td>
<td>1 year</td>
</tr>
<tr>
<td>Dean</td>
<td>Mother</td>
<td>Breast</td>
<td>Deceased</td>
<td>7 years</td>
</tr>
<tr>
<td>Gina</td>
<td>Mother</td>
<td>Melanoma</td>
<td>Cured</td>
<td>20 years</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>Prostate</td>
<td>Cured</td>
<td>18.5 years</td>
</tr>
<tr>
<td>James</td>
<td>Father</td>
<td>Prostate</td>
<td>Treatment ongoing</td>
<td>Treatment ongoing</td>
</tr>
<tr>
<td>Karen</td>
<td>Father</td>
<td>Pancreatic</td>
<td>Deceased</td>
<td>11 years</td>
</tr>
<tr>
<td>Mary</td>
<td>Mother</td>
<td>Ovarian</td>
<td>Treatment ongoing</td>
<td>Treatment ongoing</td>
</tr>
<tr>
<td>Michelle</td>
<td>Mother</td>
<td>Breast</td>
<td>Treatment ongoing</td>
<td>Treatment ongoing</td>
</tr>
<tr>
<td>Penny</td>
<td>Mother</td>
<td>Cordoma</td>
<td>Deceased</td>
<td>3.5 years</td>
</tr>
<tr>
<td>Sally</td>
<td>Mother</td>
<td>Breast</td>
<td>Deceased</td>
<td>15 years</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>Multiple Myeloma</td>
<td>Deceased</td>
<td>5 years</td>
</tr>
<tr>
<td>Stacey</td>
<td>Mother</td>
<td>Bowel</td>
<td>Cured</td>
<td>26 years</td>
</tr>
</tbody>
</table>

the development of an interview schedule or guide, which serves to ensure that specific topics of interest are covered. However, this guide is applied flexibly, allowing the wording of questions to be altered, the order of questions to be changed, and additional questions to be asked to allow the exploration of participant responses (Barriball & While, 1994; Bryman, 2004). Semi-structured interviewing is also an appropriate method of investigating the topic of parental cancer, as it well-suited for the exploration of the deeply personal experiences, allowing the researcher to gain insight into “subjectivity, voice and lived experience” (Rapley, 2004, p. 15). Furthermore, semi-structured interviewing recognises that research participants are active meaning makers and the ‘expert’ on the topic under investigation. Therefore, it provides a methodology that allows them substantial opportunity to share their experience (J. A. Smith & Osborn,

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7 Time elapsed represents the time since the parental cancer experience and the time of interview.
Such an approach is also well-suited to phenomenological studies, as the underlying philosophy holds that the participants are the experts of their own life events (Becker, 1992).

The interview schedule was written after a review of the literature, examining studies that had investigated the concept of benefit finding in cancer patients and their spouses, and an examination of the existing qualitative literature from adult children of cancer patients. At the time of the schedule development, the two theories of interest that had frequently been applied in explanation of the idea of growth arising from cancer were the theory of posttraumatic growth (Tedeschi & Calhoun, 1995, 2004) and the theory of cognitive adaptation (Taylor, 1983). As such, the interview commenced with some general questions that encouraged the participant to talk freely about their experience of parental cancer (e.g., Tell me about your experience of having a parent with cancer? What has this experience been like for you?), followed by questions that reflect the key theoretical concepts (e.g., relationships with others, personal control, and a search for meaning). While the inclusion of questions that reflect prior theorising may be strongly discouraged in qualitative research, and particularly so in phenomenological investigations, it is the opinion of the author that it was important that such issues be discussed to ascertain whether existing theories may be applicable to the experience of parental cancer, or whether the experience constituted a completely separate/different phenomenon that was not adequately explained by existing theories. It is also noteworthy that, while questions were phrased around existing theoretical structures the author made no hypotheses concerning whether such features would be present or applicable, and was rather asking to determine whether existing theories had any validity with this cohort.

An initial pool of questions was submitted to the author’s supervisors, and a meeting was held to discuss their suitability for inclusion and their wording. As a response to this process, several questions were discarded, some items were revised, and the ordering of the questions was altered. After these revisions had occurred, the author conducted a pilot interview with a colleague, who has a history of conducting qualitative
research, and whose mother had been treated for breast cancer. At the conclusion of this interview, feedback was provided; some items were further revised, and additional discussions were held with the author’s supervisors. At that time, it was agreed that the interview schedule was suitable for use, and it was submitted to the Charles Sturt University Ethics in Human Research Committee for approval. The ethics committee raised concerns about some items, specifically those questions that related to the factual background of the parent’s disease (i.e., time since diagnosis, treatment undertaken), arguing that such questions violated the privacy of patients who had not consented for participation. The items were removed and replaced with a general question inviting the participant to talk about their parent’s cancer, on the grounds that such an open question would enable the participant to reveal as much contextual information as would be typical for that person, and as such would represent the family’s level of openness, when telling others about their situation. This modification was approved by the Ethics Committee (see Appendix D) and recruitment commenced.

The interview schedule was divided into several sections dealing with different key issues (see Appendix E for complete interview schedule). These sections were: (a) experiencing parental cancer (e.g., tell me about your parent’s cancer?); (b) family relationships (e.g., can you describe how you believe parental cancer has changed your family, if at all?); (c) coping (e.g., How did you adjust to your parent’s cancer?); (d) cancer and adjustment related cognitions (e.g., What are some of the cancer-related thoughts or beliefs you used to help you deal with your parent’s cancer?); and (e) personal health behaviours (e.g., Do you think that your parent’s diagnosis of cancer has altered the way you look at your own health?).

4.3.3 Procedure.
After advertising and promoting the study, participants were asked to contact the author. Once their eligibility for participation was checked, the author forwarded an information statement to the participants and a time was set for the interview. Most interviews occurred in the workplaces of the participants, or in the author’s office at Charles Sturt University. However
two interviews were conducted at other locations (i.e., participant’s home, a hotel room) due to the author having to travel to interview the participants. On all occasions, the participant determined where the interview should be held.

At the commencement of each interview, an informed consent form was signed, and the participant was given an opportunity to ask any questions about the project. After consent was obtained the interview commenced. While the basic interview structure was followed, the interviewer approached the schedule flexibly to allow for issues to be discussed fully, and for additional topics to be explored. The duration of the interviews ranged from 28 minutes to 75 minutes. All interviews were recorded with a digital note-taker and transcribed verbatim by the author. During the transcription process, all identifying information was removed from the transcripts to protect participant anonymity, and all participants were assigned a pseudonym.

**4.3.4 Data analysis.**

The transcripts were analysed using an interpretive phenomenological approach as outlined by J. A. Smith and colleagues (see J. A. Smith et al., 1999; and J. A. Smith & Osborn, 2003). Analysis began with a single transcript being read, with the author making a note of any features of the transcript that seemed interesting or significant. The transcript was read several times in this manner, with additional notes being made on subsequent readings. At this stage the notes served as summaries of the content, identifiers of connections between content, highlighting similarities, differences and contradictions, points pertaining to the language used, and the author’s initial responses and interpretations of the transcript (J. A. Smith & Osborn, 2003).

When subsequent reading of the transcript threw up no new notes, the author moved to the next stage of analysis, which involved listing and articulating emerging theme titles. This step required the author to transform the initial notes into succinct phrases, which captured the essence of what was emerging from the transcript (J. A. Smith et al., 1999). It is essential
that, at this stage, the theme titles begin to reflect both the actual content that was provided by the participant and a higher level of abstraction that represents psychological thought and theorising (J. A. Smith & Osborn, 2003).

The next stage of analysis required the author to examine the emerging themes for possible connections. To facilitate this process, all emerging theme titles were listed, and possible links were tentatively formed. After checking back with the transcript, it was determined whether such links were appropriate, or whether the theme titles needed further refining to specify their content. This process was continued until the emerging themes were organised into clusters. This process involved an active interaction between the author and the text, as the researcher utilises their interpretive skills, whilst constantly checking that such interpretations are accurate reflections of the participant’s words (J. A. Smith & Osborn, 2003). Once clustering was completed, a table of themes (the master list) was produced to represent the theme groupings. The clusters were named so that a superordinate theme was created, typically consisting of several sub-themes. During this stage, some of the initial emerging themes were allocated to the side, as it was becoming evident that they did not fit the emerging structure, or there was limited evidence to support them. Such themes were not however deleted, as they may be supported in subsequent cases.

After the first transcript was analysed to the point of constructing a master list of themes, the author turned to the next transcript and repeated the process again. Each transcript was treated as a ‘new first case,’ and the author attempted to minimise the influence of themes identified in prior cases on each analysis. As J. A. Smith and Osborn (2003) note, such a process requires the researcher to be disciplined so that they are able to recognise duplicated themes in the described experience, whilst also remaining open to new emerging themes and issues. Once each transcript was analysed, the master lists were then read together and similarities and differences noted. Themes, which were present in some interviews, were tested against transcripts, in which such themes were absent, to determine
whether they were present and had been overlooked, whether the participant expressed an opposing view (i.e., a negative case), or whether they were actually not described by that participant. Furthermore, if the same theme was present in two or more transcripts, each was checked to determine whether the theme was an accurate representation of the participant’s voice, or whether some distortion had arisen in the analysis of multiple cases. Where necessary revisions were made, new themes were fashioned until a master list was created that represented the main themes present across all participants in this study (see Appendix F for an example of a worked transcript and the emerging themes).

In summary, this chapter has outlined the qualitative methodology employed in Study One, discussing the philosophical foundations of phenomenology and symbolic interactionism, and how they combine in the creation of the interpretative phenomenological approach undertaken. The chapter has also highlighted the steps taken within the research process to ensure methodological rigour, namely recognition of researcher subjectivity, the use of a reflexive journal, the examination of negative cases, and the discussion of interpretation with an academic supervisor as a credibility check. A detailed description of the study method followed, detailing the participants, interview development, ethical considerations, and data collection procedure. A thorough breakdown of the data analysis procedure is outlined, providing a step by step guide to the interpretative phenomenological analysis performed. The next chapter presents the results of Study One, and discusses them in light of existing research and theory.
Chapter 5: Study One Results and Discussion

This chapter presents the findings of the interpretive phenomenological analysis conducted on the data obtained from 11 interviews with adults whose parents have cancer. It begins with a review of the key aims of Study One, followed by a brief introduction of the themes and their sub-themes. A more detailed presentation of each theme is then included, with each theme being demonstrated by data extracts to bring forth the voice of the participants. The discussion section of the chapter relates the current findings to the existing empirical and theoretical literature, and summarises the key pattern of relationship between themes that appears to have emerged from the data. The limitations with Study One are also noted, and areas for future research highlighted.

5.1. Study One Aims and Summary of Themes

The primary aims of the first study were to:

1. Confirm the presence of perceived benefit finding in adult children of cancer patients;
2. Investigate the types of perceived benefits reported by adult children, and assess how such benefits fit within existing classifications of benefit finding (as proposed by Tedeschi and Calhoun, 1995, and Thornton, 2002); and
3. Examine the data to ascertain if one particular theoretical view of posttraumatic growth seemed to emerge from participants descriptions of parental cancer.

A total of seven themes emerged from the data, falling into two broad categories: (a) benefit finding (four themes, see Figure 5.1), and (b) negative aspects of the experience of parental cancer (three themes, see Figure 5.2). Importantly, for the current thesis, all participants identified a number of potential benefits. The number of reported benefits ranged from four to 11, with a modal number of seven perceived benefits (reported by three out of 11 participants). However, while benefits are possible, the study

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8 The themes, which demonstrate the negative experiential aspects of parental cancer, will be referred to as negative themes from this point forward.
also identified a range of negative themes that provide further insight into the parental cancer experience. Typically, each of the seven themes was comprised of several sub-themes, indicating the breadth of experience that arises during parental cancer. The first theme of transforming the relationship with the sick parent describes positive changes that arose in the relationship between the adult child and the parent with cancer. This
included elements such as an enhanced sense of closeness, improved communication, increased involvement in each other’s lives, and increased respect and appreciation of the parent. The second theme, family matters, reflects the change in emphasis placed on family by participants, and an acknowledgement of some positive changes in relationships with other family members. The third theme of altered life priorities represents that participants reported changes in outlook that arose from having a parent with cancer, encompassing multiple life domains such as interpersonal relationships, life philosophies, and career. The final benefit theme, personal development, reflects changes in one’s view of self, noting positive changes and growth in the areas of maturity, compassion, assertiveness, while also encompassing changes to health behaviours.

The negative themes reflecting broader descriptions of the experience of parental cancer included the theme of experience intensity. This theme acknowledges the participants’ struggle with their parent’s illness, examining the emotional impact of diagnosis and the longer-term emotional difficulties that arise along the illness journey. The second negative theme of grief and loss is strongly connected to experience intensity, but examines the sentiments expressed which are clearly associated with losses arising from having a parent with cancer, and having to bear witness to parental suffering. The final negative theme of involvement in caregiving encompasses both the objective and subjective aspects of caregiving, including changes in role and problems arising from caregiving. The following Sections 5.2 through to 5.8 provide a detailed examination of each of the themes.

5.2 Transforming the Relationship with the Sick Parent

One of the most commonly cited benefits of parental cancer (mentioned by eight participants) is represented by the theme transformed relationship with the sick parent. According to the data, this theme may be defined as the presence of positive developments or changes in the relationship between the child and the parent with cancer. The two sub-
themes that comprise this theme were: (a) enhanced relationship with sick parent; and (b) respect and appreciation.

5.2.1 Enhanced relationship with the sick parent.

For some of the participants, the change in their relationship with their sick parent manifested itself as an enhanced feeling of closeness, and a deeper sense of understanding each other’s needs. For example, when asked to define what “being closer” to her mum meant, one participant stated “I know how she is feeling without her saying” (Mary). For another participant, the cancer experience led her to have increased contact with her sick mother, and through this contact she was able to learn more about her mother and her past, as her mother “was telling me stories I hadn’t heard before” (Michelle). Michelle also noted that she was trying to be “more interactive and a bit more responsible as a daughter,” and was actively putting in an effort to be “nicer to my mother.”

For three of the participants, their parent’s illness provided a catalyst to resolve old conflicts and grievances, and through this resolution they developed an enhanced connection. For Cathy, her father’s diagnosis of a brain tumour ended his working career, and provided an opportunity for father and daughter to reconnect. As Cathy describes:

... something I kind of noticed at the time and I am coming to terms with afterwards, my dad could be a hard person to live with at times, I mean he was a great guy but before he got sick, it was my dad is a great guy but ... I had a bit of a difficult relationship with him when I was a teenager, ... He stopped working after this fit ... and immediately he was easier to live with, he de-stressed, he mellowed. But my relationship with my dad, I guess we kind of got to know each other adult to adult ... after I moved out of home [shortly after diagnosis] and while he was sick, so I liked the person my dad was much better after he was sick.

For James, his father’s prostate cancer signified the re-invention of the father-son relationship. James had felt that his father disapproved of his career in professional sports. However, through connecting with his Dad during his illness, he saw a transformation in his father’s attitude, as is evidenced in the following extract:
He never thought baseball coaching was a job and now, when I told him about, I had an opportunity to go [overseas] and do some things, and get a job in the United States coaching and he is eager for that now... he is much happier for me to go and do things that I want to do ... now he is more into me making happy decisions I guess so that is the biggest change, or one of. We do things now, we didn’t before, we worked, we talked about working, but we have played golf, we have talked about buying a boat together.

In this case, the diagnosis of cancer appears to have provided a wake- up call for these men to re-evaluate the importance of each other in their lives, leading to changes not only in outlook, but also in how they interact. James further acknowledged that the communication between his father and himself had improved, and that he perceived that he was one of the few people his father talked to when he was trying to cope. As James summarises: “we have had the best conversations we have ever had in the past few years.”

A second participant, Beth, also described changes in her relationship with her father, noting that the degree of closeness between them had changed for the better, and that she now enjoyed spending time with him. As Beth commented:

we had a lot of ups and down and we weren’t very close at all . . . because of this and he is actually a different man, he is someone that you actually enjoy visiting and so I think if it hadn’t happened, I mean he could have lived for another 60 years perfectly well and no one really would have cared, yeah but because of this everyone is that much closer and has enjoyed him more and enjoyed life more and (long pause). Well as I said it has been difficult, like he just wasn’t somebody, like he always did everything for us, he was a good father and a good provider and all the rest, but he could be quite difficult (laughs) and now yeah we do get on, you know like I used to dread getting stuck with him on the phone before and now he can have a joke and a good conversation, and yeah it’s a lot better relationship.

For participants who felt that they already had good relationships with their sick parent prior to diagnosis, there was still clear evidence to suggest that the parent-child relationship was altered through the cancer experience. For example, Stacey, an only child dealing with her mother’s
diagnosis of bowel cancer shortly after her father’s death, recognised the significance of her relationship with her mother. Stacey reflected:

. . . the way that I felt about her and wanting to be with her changed . . . I suppose more of an appreciation of her, not a deepening of love or affection, probably more demonstrative in it and much more in giving to her rather than taking all the time.

This enhanced connection with her mother has extended to the current day, some 20 years after her mother’s illness, with Stacey and her mother currently living together and reporting a great relationship, suggesting that changes that emerge during this intense period may hold great longevity.

5.2.2 Respect and appreciation.

The second sub-theme to emerge was that of increased respect and/or appreciation for the sick parent. The experience of cancer provided numerous opportunities for adult children to recognise the pivotal role their parent held in their family, as well as an increased insight into their parent’s personal strengths. For example Michelle identified that her mother was “the core and the lynch pin and the concrete under flooring of the whole system [of her family],” while she also acknowledged her mother’s worth and importance as an older individual, commenting “…most people say that at 76 she is pretty old, done her dash … had a good innings and all the rest of it, but from my perspective my mother is crucial.”

Mary was also impressed by the changes she saw occurring within her parent’s relationship, as her sick mother transformed from a submissive wife to a woman who would stand up for herself. When asked if anything positive had emerged from the cancer experience Mary clearly expressed her newfound admiration for her mother by commenting:

Her relationship with dad and the fact that she is now standing up for herself, that the cancer has given her the strength to do that whereas before she would never, never question him, would never have answered him back, whereas now it has given her the strength and I think yay!
For two participants who lost their parents, there was also admiration in how their parents approached their death and their consideration of the practical aspects of dying. For Dean, he respected his mother for the decisions she made in relation to her care and the disposal of her assets. Sally, who lost both parents to cancer, reports finding inspiration in her parents’ struggle. Her mother died at home, after a long and secret battle with breast cancer, and while Sally acknowledged that keeping her disease a secret may have affected her prognosis, she also admired her mother for the dignity, strength and courage that she demonstrated. Sally stated “she actually did quite well even though I think she did herself a great disservice [by keeping it a secret] . . . I think the fact that she controlled it and she managed it for a very long period of time.” In relation to her Dad, Sally has great respect for his decision not to treat his leukaemia, or seek out the suspected primary source of the cancer. These two experiences appear to have greatly affected Sally, who herself has had positive testing for breast cancer. Sally reported that her parents provided her with inspirational role models, especially her mother, whom she was determined to emulate, stating “whatever she did go through, she did with a lot of dignity and there was no way I was going to be a blubbering mess.” There is also evidence that Sally’s father’s actions to make strong decisions regarding his cancer’s treatment influenced Sally’s attitude towards controlling her own experience of positive cancer screening, when she stated “I was going to have control of this process, and nobody was going to tell me how to manage it, I would take the information and I would make up my own mind.”

5.3. Family Matters

The second benefit theme, family matters (mentioned by 10 participants), may be defined as a noted change by the adult child in terms of a more positive attitude towards family, and/or enhanced familial relationships. The four sub-themes that comprise this theme were: (a) valuing family; (b) improved relationship/s with other family members; (c) benefits for grandchildren; and (d) establishing one’s own family.
5.3.1 Valuing family.

The most commonly mentioned benefit in family matters was an enhanced sense of importance placed on family, a valuing of one’s family that, in essence, arose from the reflection that family is central to one’s life (seven out of 11 participants). There was recognition that family provides important permanent connections to others (Cathy), and that family provides one with love (Gina). One of the more dominant aspects of this sub-theme was the notion that family requires time, and that to maximise the benefits one has to put time and effort into the family unit. For example, Karen reflected:

*I guess it has, you know made me more aware of family and the importance of being, of doing things that you need to with your family, spending the time with your family, telling them that you care about them.*

Spending time with family was also mentioned by both of the male participants in the study, and James asserted that the meaning he has found from the parental cancer experience was “*doing better at family stuff,*” which he detailed as “*I have seven nieces and nephews which is not a great deal but making an effort to see them and my brothers and my sister.*” The experience of his mother’s breast cancer gave Dean the opportunity to reflect on his upbringing, to recognise the faults of his father, and prevent himself from making the same mistakes with his family. Dean reported that he perceived his relationship within his own family (i.e., his wife and children) to be closer, and that he “*certainly spend[s] a lot more time with my family than I used to.*” It is, however, acknowledged that, during his mother’s cancer there was a certain degree of strain within this family unit, as he felt torn between caring for his mother and his responsibilities to his wife and young children. Therefore, the data seems to suggest that, while the cancer experience can lead to an increased awareness of the importance of family, in reality, it may also create strain within the unit (for further discussion see Section 5.8.4).

5.3.2 Improved relationship/s with family members.

Four participants reported beneficial changes in their relationships with their healthy parent as an outcome that arose from their experience
with parental cancer. Mary described in detail the transformation of her healthy father from a typical strong male to an affectionate and needy individual. Mary states:

*I am even shocked when sometimes he leans in for a kiss, you know he has never been that type of man, and when he shows affection like he puts his hand on my knee, or a hand on the shoulder ... or he does cuddle me, he does stand there and cuddle me, and I think Oh my God, this is not my Dad...*

Karen also noted great changes in her relationship with her mother after her father died, especially in the realm of improved communication, increased contact, an enhanced sense of closeness, and being able to express love and affection. For example, Karen reported

* I think I can tell her I love her more than I used to be able to and she can say that to me, and umm, she, yeah we can talk about stuff, about Dad too and when I was only over there about five weeks ago moving her in to her house she just sort of said you know I could never have got through this whole process without you, you’ve just been wonderful . . . So that has made us more close, I speak with her, I mean we got into a pattern of speaking every Wednesday night regularly.*

However, the suggestion that parental cancer can contribute to an improved relationship with the healthy parent should not be viewed as universal, as two participants expressed a less than optimal relationship. For example, Penny reported feeling high levels of resentment towards her father, who she believed did not adequately support her mother as she was dying. Her feeling that her father “wasn’t giving his best to mum” had seen an increase in conflict between the father and daughter, which Penny attributed to her mother not being there to “act as a buffer.” In another case, Dean recognised that his relationship with his father had become strained, again due to resentment about issues relating to his mother. However, Dean acknowledged that he does hope to improve his relationship with his father in the future, as is suggested in the following statement from Dean; “I don’t make the same effort as I would have done before for him, and I don’t think that is a good thing, I would like to change it, I feel that I will change it in time ...”
For those participants who described positive changes in their relationships, this positive transformation was usually accompanied by an increased sense of responsibility, worry about how their healthy parent coped with their partner’s illness, or increased care needs of the healthy parent, such as involvement in financial matters. For example, Cathy stated that the loss of her father had led her to “worry more about losing my mum,” due to concerns that “without your parents you lose connections, you lose permanent connections.” Mary recounted how she had to assist her healthy father adapt to independent living while her mother was being treated in a city hospital, hours from the family home. Her dad was staying in accommodation near the hospital, and Mary reflected that she had to teach her father a range of self-care skills, as is evidenced in the following extract:

I went basically to guide dad because we stayed at . . . some lodge that was near the hospital, but basically to show him how to get from the lodge to where mum is everyday, so I went there for two weeks, and everyday we would go through the routine, you know we go here, . . . getting to shops to where to buy stuff because he has never ever been in the city . . . no idea, where to buy stuff, how to make it, how to do his laundry in the lodge, where to walk at the back of the hospital to mum’s floor, where to go for a meal because he wouldn’t eat . . . It is all those little practical things because he has never been exposed to city life and . . . everything was quite new.

When concerns about the healthy parent arose, the change in the relationship between the healthy parent and the child could be perceived as both a benefit and an increased demand on one’s time and emotional resources. This is highlighted in the following exchange between the author and Karen:

K: And it has changed my role with my mother
I: The change in your relationship with your mother, how would you evaluate that, like do you see it as a positive thing or a negative thing or a bit of both?
K: (pause) It is positive, but the burden of it has fallen to me.

This exchange is rather telling, because whilst Karen is pleased with the enhanced closeness with her mother, and she reportedly enjoyed the affection that they share, there is also the perception of additional responsibility, as is suggested by her use of the word burden in her evaluation. Later, Karen identified that she believed she was “definitely
"going to be that sandwich person between your teenage kids and your parents," which supports the suggestion that the changes in the relationship with the healthy parent can carry both positive and negative aspects.

There is also evidence to suggest that participants (four out of the 11) found beneficial changes in their relationships with their siblings and extended family members. Importantly, for Stacey, an only child, she reported an increased level of support from her grandmother and uncle during her mother’s illness, specifically that her grandmother provided more instrumental help, such as “doing the washing, doing the washing up, whatever she could do to help,” and that she developed an enhanced bond with her uncle. Significantly, this positive change with her uncle continued at the time of the interview, and Stacey commented “he is still extremely close with me because of it I think. I think he felt that it was an awful lot for someone my age [18] to have to go through.”

Generally, when beneficial changes were identified in relation to siblings, the participants identified feeling closer to at least one of their siblings, or trying to protect and look out for their siblings. Sally felt an increased closeness to her sister, which emerged due to increased contact, as is evidenced by Sally’s statement “It brought my sister and I closer together because we were on the phone and caring for the two of them, but organising it between the two of us so that probably brought my sister and I closer together.” Penny also described beneficial changes in her relationships with her brother and sister, when she stated “my relationship with my siblings is a lot stronger, it was never fraught but it wasn’t particularly close and we did a lot of talking during mum’s illness ...” Indeed, her mother’s cancer provided Penny with an opportunity to heal the relationship she had with her brother, who she believed she did not know prior to her mother’s illness. This improvement has continued through to the time of the interview (four years after her mother passed) and Penny recognised the supportive role she played in her siblings lives, as evidenced by her comment:

...there are things happening in both of their lives, my nephew, my sister’s son has a serious illness ... my brother’s marriage is breaking up ... so now I am realising that now it
is my role to be a bit more stable and support them a bit and wanting to do that, being comfortable about doing that.

Again, however, changes in relationships with one’s siblings were not found to be universally positive, with two participants reporting increased feelings of resentment towards their siblings. In both cases, this was due to a perceived inequity in terms of care responsibilities, as both participants reported that they did the majority of the caring for their sick and healthy parents, while their other siblings were perceived as taking minimal responsibility. For example, Mary felt that her brother and sisters should have been more involved with their mother’s care. Their refusal to help had placed her in the role of primary carer, a role she had taken on to support her mother, but which she did not enjoy, as is evidenced by her statement:

I don’t like it [being the main carer], I don’t like it and I have said to [my siblings] look I’m the baby, you’re all older, . . . but they just don’t help, they are now considering that she is better but when she was in her worst stages none of them came near her, they thought it would be best if they just stayed away cause I’m there, but I didn’t go in there blazing and say I’m going to do it all.

Additionally, some participants felt increased levels of worry for their siblings (three out of 11), particularly in regard to the perceived risk of the sibling getting cancer, or the intense exposure to the illness arising from the sibling still living with the sick parent. This is exemplified in the statement by Beth:

You could say, I have a younger sister and she is still living [in the same town as her parents] and she is very close to it all, she has only just moved out of Mum and Dad’s, but she is still spending a lot of time there . . . sort of looking out more for her and trying to be more aware if she is having a tough time.

5.3.3 Benefits for grandchildren and establishing one’s own family.

Another interesting finding to emerge from the data relates to the offspring of the adult children, the grandchildren. Three participants were able to identify that the relationship with their parents and their children had
been altered by the cancer experience. For example, Beth, who had a strained relationship with her father until his illness, commented that “with the kids he is a million time better grandfather for them, and yeah he has been wonderful for them.” The other main change mentioned by the remaining two participants relates to more time spent with grandparents. Indeed, Sally’s father moved in with her family after the death of his wife, resulting in a plethora of perceived benefits for Sally’s children, including acceptance of older people, earlier independence, emotional support from a non-judgemental adult, and enhanced empathy. Sally described these benefits in the following extracts:

That was hugely positive for my children to have the next generation living so close . . . they accept older people, they can relate to older people, they understand family far better than a lot of their peers . . my children have had one of their grandparents with them for a large part of their lives, a large chunk of their formative years.

They learnt a lot more independently because he was there to back them up . . . it was very good for them to have that senior person there who was just that one generation removed, little bit more gentle, a little bit more knowledge, little bit more support, it was very valuable for them, and we would not have had that if mum had not died of cancer.

Furthermore, Sally identified her children’s exposure to illness and death in a loving environment as a huge benefit in teaching her children important life lessons, as is evidenced by her statement “my children have been able to have this exposure to life and death without it being horrible and traumatic, it’s been very loving and it’s been just everyday life.”

Importantly, the two participants, who were unmarried at the time of data collection, both identified starting a family as a key issue for themselves. James was eager to start a family so that his children could get to know their grandfather, and this represented a significant change in his attitude towards becoming a father. James stated:

There are probably personal things that I have added to that list that were never on the list, so a grandchild which is something that I wanted, I wanted a family but I couldn’t, I just wasn’t drastically worried if it didn’t happen and that has probably changed.
Cathy recognised the importance and permanence of family connections in her life, and therefore recognised the need to create a family of her own. Cathy described this as:

*For me, what I need is family looking forward . . . I personally need family as a connection, as a reason to continue to do things, and I suppose you lose one parent and it’s not quite three strikes and you’re out, but it’s a severing of a connection to the world that alerts you to the need to continue making connections.*

5.4 Altered Life Priorities

The third benefit theme to emerge from the data is *altered life priorities*, defined as positive changes in attitude relating to outlook in life, core values or life philosophy. This attitudinal change was frequently accompanied by behavioural changes in relation to one’s life goals. The four sub-themes of this theme were: (a) valuing people and relationships; (b) reappraisal and perspective; (c) changes to work and career; and (d) embracing life and adventure.

5.4.1 Valuing people and relationships.

The most commonly mentioned benefit within this theme (six out of 11 participants) reflected the participants’ changing attitude towards valuing people and relationships. While there was some degree of overlap between this sub-theme and the themes relating to improved family relationships, there are also features that distinguish it from family-related matters. Typically, this sub-theme represented a general change in outlook, an acknowledgement that people are important in the individual’s life, and that relationships require effort to be successful. This sentiment was represented by Michelle, when she stated “it makes you realise that you really should put effort in, in talking to people and showing some support.” Similar sentiments were reflected by Karen, who spoke about not having time for “negative relationships with people because things are too short,” and Gina who believed her parents cancer (both parents were ill) had “allowed [her] to see things differently, to accept people unconditionally.” Beth mentioned that she recognised the support provided to her by her friend, commenting “My best friend gets a lot of it, just sort of we all just pull in together and I guess just sort of support each other.”
Another aspect to this sub-theme was that, for one participant, his father’s cancer led him to reflect on his personal relationships with women and his previous inability to create meaningful relationships in this area, partly due to his career focus, but also due to his attitude. James reflected:

*I didn’t value my personal relationships outside, I am very conscious of what my family has contributed to my career, to my baseball career, umm they have sacrificed a great deal for that, but my personal relationships with women have been quite flimsy at best, quite superficial and I am endeavouring to make that much better.*

His father’s cancer, and the subsequent changes in his parent’s relationship, also provided James with a role model relationship to aspire to, with his parents displaying enduring love and concern after more than 45 years of marriage.

It is also important to note that this increased acceptance and valuing of people was also present between one participant and relative strangers. Penny noted that, during her time with her mother in hospital, there was a range of interactions with people that “reminded [her] that a lot of people are good people.” She recounted a story of a young man, who was admitted to intensive care at the same time as her mother, after he had been involved in a serious motor accident. Months later, when they met once more, Penny reported that the following exchange occurred:

*I approached the father and asked if he was his son and that I was around when he came in and it’s really nice to see him ... and he asked about mum and I said we were letting her go, that she was going to die and he just took my hand and squeezed it, and it was just so nice, like it didn’t have to be anything else, it was just an acknowledgement of the pain we had both gone through, and umm yeah mothers do die and sons shouldn’t you know, I think about that stuff.*

This exchange, and others like it, appeared to be important for Penny, enabling her to see the kindness of others, and providing her with support during an emotionally difficult time.
5.4.2 Reappraisal and perspective.

There is evidence in the stories of seven participants that parental cancer contributed to some changing of the individual’s outlook on life. Sentiments along the lines of “live for the day” (Gina), “I don’t care what people say” (James), and “I don’t take life so seriously” (Mary) were frequently cited as positive changes that had arisen in response to their experience of parental cancer. Gina, who had faced losing both of her parents to cancer, had become quite philosophical, recognising the illness as a learning opportunity. Gina commented:

*If anything is sent to you like an illness like that in the family, that you can learn so much from it. You can either be very negative about it and see the worst side of it, or you can see the better side and what you have learnt from it.*

Gina has been able to reconceptualise her parent’s cancer as an experience she had learned from, both in terms of who she was and how significant her family are to her. She also reported increased compassion for others, and an optimistic outlook on life that she has applied to her own experience with chronic illness.

Beth discussed how her father’s leukaemia had helped her to identify the need for balance between work and personal life, noting a new attitude to embrace life before illness prevented you from completing other goals. Beth stated:

*I guess it really makes you see, you know don’t put things off. Dad was always, you know just work and do nothing and he says himself that his father told him as he was dying you know don’t do what I did and work yourself until you die and enjoy nothing . . . he ended up being able to get a medical retirement and so he tried to do stuff, but he really left it too late anyway. Yeah so I guess not, just to do what you want to do, live life.*

5.4.3 Changes to work and career.

A third sub-theme that was present in the data was evidence of changes to work patterns and career paths. For some participants, the changes related to work load and intensity, such as Dean who acknowledged that he no longer works with “the same rabid intensity that I used to” to
ensure he had time for himself and his family. Beth, a student, also cut her study load to allow greater flexibility, in case she needed to travel to be with her sick father; however, she did not perceive this as a beneficial change, but rather a necessary action.

Additionally, there were two participants who reported substantial change in their work habits. Karen and her partner sold their home, left secure long-term employment, and moved their young family to a rural area to become “pioneers” and develop a property that had been their dream. Although Karen acknowledged the professional implications of this move with phrases such as “we threw away our security” and “I went back to the bottom of the rung,” she also identified that the experience was a great opportunity for her family as a “whole renewal type thing.” Karen reflected “it was a great thing because we created something together as a family that we had and that was new.” Importantly, Karen believes that her father’s cancer “actually caused us to leave the jobs we had,” implying that her parent’s cancer was a direct catalyst for positive change. This direct causal attribution confirms the suggestion that parental cancer may bring about life changes that give rise to beneficial outcomes for the adult child.

The second case involving a substantial change in career plans was James, who was involved in professional sports and therefore required to travel frequently. To ensure that he was available to care for and support his father and mother during his father’s treatment James turned down offers of overseas employment, eliminated all work-based travel, and accepted a job that would see him living closer to his parents. In addition to the practical changes, James also identified that his experience with his father’s cancer changed who he was, and this has led to improvements in his job, as reflected in the following passage:

_I am much better at this job, I am much better at my old job than I ever was, I was quite intense as a coach, and the big jobs, very intense, very full on all the time and I made people work for me, I made them work all the time and that stopped, no need for that, especially when you coach baseball and you get paid pretty good money to do that, it is a game so yeah, I am better with my work._
James appeared to have recognised that life is about more than work, which suggested that he had altered his priorities. Baseball, which he was intensely passionate about, was now perceived as “a game,” and there was the suggestion that he was more understanding of the circumstances of people and demands less of them in terms of time spent at work. It is also important to note that James perceived that the more balanced attitude, he had developed in response to his father’s cancer, to be a beneficial outcome that had improved his professional life. Another interesting theme present in James’ story was his recent activities as a cancer advocate. At the time of his interview, James had integrated supporting cancer causes into his professional sporting activities, participating in fundraising, raising the profile of cancer agencies in media interviews, and organising events to increase awareness of cancer within the community. This may be seen as a further reflection of James’ balanced attitude, in his recognition of the potential for giving back to the community that is afforded to him by his position in the sporting arena.

5.4.4 Embracing life and adventure.

Another aspect of the altered life priorities theme is the sub-theme of embracing life and adventure. For two participants, Karen and Penny, their experience of the death of their parent to cancer saw them adopt an attitude of embracing life. Karen, as suggested earlier, saw her and her family becoming “pioneers” as they engaged in an adventure of “renewal.” Penny’s changes have been more subtle, more an opening up to ideas and activities that she would not consider previously. She described herself as “probably likely to be a little more adventurous” and, at the time of the interview, had planned to travel overseas on her own, and begin participating in camping trips with her partner. For other participants, there were no big changes in activities, but rather an enhanced sense of valuing life, recognition of the fragility of life and the impact that loss has on one’s family. Dean acknowledged that he had been a “risk taker” in the past, and the loss of his mother saw him “slowing that part of me down because you see the effects of someone not being there anymore and what an effect that has on a family.”
5.5 Personal Development

The final benefit theme that emerged from the data was personal development, defined as perceived positive changes to one’s personal qualities, view of self and behaviours relating to personal well-being. The six sub-themes of personal development were: (a) compassion; (b) emotional maturity; (c) independence; (d) wisdom and insight; (e) confidence and assertiveness; and (f) cancer related health behaviours.

5.5.1 Compassion.

Five of the participants made statements that indicated that they had developed an increase in compassion through their experiences. The participants reported being a “better listener” (James), and having increased understanding that made them a “better person” (Gina). The experience also provided an opportunity to learn about grief for Penny, who reflected:

*I think probably a much greater awareness of what it means to other people when someone dies, you know I have friends whose sister has died, whose parents have died ... and I sort of gave sympathy about it but didn’t really get it and, so it has given me a greater awareness of that. Also just a greater awareness of how someone’s response to death is just, and to the care and illness as well, is just so individual.*

Similarly, Cathy reported developing an enhanced sense of compassion, which could help her interact with others facing a similar situation. Cathy commented:

*I’ve learnt how perhaps you deal with someone else in the situation. People talk about being emotionally scarred, well sure life scars you, but it is the scars that give you character, it is the scars that will allow you to tell other people who are hurting, who are ripped open that it is all right, you will heal, this is how I healed.*

An increase in compassion was not universally reported, and one participant openly stated “I think I am probably less tolerant of other people who wail and moan” (Sally). This sentiment reflected Sally’s attitude that illness is a typical part of life, which affects everyone to some extent. She had also been involved in caring for both of her parents, who died from cancer, and from this developed a respect for the composure and strength
that they displayed throughout the duration of their illnesses. Subsequently, Sally had reduced compassion for those who she saw as dealing with their illness in an undesirable manner.

5.5.2 Emotional maturity and independence.

Parental cancer was also identified by four of the 11 participants as a time for ‘growing up’ in terms of their emotional development and independence. A new level of emotional maturity was achieved by some, arising largely from struggles associated with situations that needed resolution. For example, Cathy was faced with extended periods away from her sick father, due to her work commitments, and struggled to deal with the perception of others who implied she should not leave her father. Rather than falling into a pattern of feeling guilt and remorse for her actions, Cathy identified that her work was important to her coping, and therefore she needed to accept her decision to pursue professional goals. In the resolution of this quandary, Cathy felt more assured of her feelings and was able to recognise that she was the person most suited to making decisions that affect her, as is evidenced in the following extract:

She [her supervisor] was like do you think you should be here? So this is all coming to, you don’t have to react how people think you should react, you should react how you think you should react, where it is that you are at the moment, ok take on board what they are saying because what you think now you may look back on it and go why didn’t I do that, so pushing yourself to work, I must work, I must continue, I must completely be as normal as possible doesn’t necessarily always work, some days you just don’t cope and that’s ok, and you do have to take extra time, go to see your family more often if you are away from family, but it is only one aspect.

Cathy also reported an increased sense of personal strength, noting that she had a greater understanding of her coping ability. Cathy stated:

One of life’s greatest skills is the ability to make the worst thing that could happen to you one of the best things that could happen to you, and while I’m not going to pretend that losing your father could ever be a good thing, but you take the best from it, and I learnt that I can cope.

The experience of her mother’s bowel cancer when she was aged 18 transformed Stacey from a wild teenager, who was “angsty and prone to
temper tantrums," into a mature and independent adult, who she now describes as “being boringly, dully responsible,” largely due to the sharp increase in responsibility that arose during her mother’s illness. During the cancer experience, Stacey found herself responsible for herself, her mother’s business, her studies, and organising other family members including her grandmother, aunt and uncle to ensure her mother’s care needs were met. Stacey stated “It’s one thing to be mature and independent, and it’s another thing to be responsible, and it was a big growth in responsibility, which was good.” In the light of the above extracts it may be suggested that parental cancer played an important role in the individual’s maturation, both in terms of increased emotional maturity and the practical aspects of independence and taking on responsibility. As Karen summarised, “I [didn’t] want to think about growing up and it just made me.”

5.5.3 Wisdom and insight.

An additional sub-theme in the personal development benefits was wisdom and insight. Gina identified her experience as a “learning curve,” which made her “a lot wiser” as she gained insight into human infallibility. For Dean came an understanding of the impact of loss on family, while Penny, in her struggle to find meaning in her mum’s cancer, recognised her resilience and the strength that gave her. Sally took a lot from her experience with her mother’s cancer, and her mother’s decision to keep her disease a secret, and applied this new insight to her own situation, when she faced a potential diagnosis of breast cancer. Sally was determined that her children would be informed, identifying that “it is important for them to see it [cancer] being dealt with...” Therefore, through the stories that these participants shared, it is suggested that wisdom may be developed in a range of areas, including personal aspects of life (e.g., Penny), interpersonal relationships (e.g., Sally and Dean) and humanity in general (e.g., Gina).

5.5.4 Confidence and assertiveness.

Two participants attributed changes in their self-confidence and assertiveness directly to their experiences with their parent’s cancer. On several occasions, Penny believed her mother received poor care and found
that she eventually felt the need to speak out and question what was happening. Penny commented:

*I think in some ways I have a greater confidence in some things ... confidence in not letting a health system run itself so to speak, in being able to say well hang on a minute, what is this? Why are you doing this? And challenging things, and that challenge may simply mean getting more information and that is all I need or having the care better, better quality of care.*

Penny eventually made the decision to lodge a complaint against one hospital to the Healthcare Complaints Commission, and later formally complained against the Commission itself for their inaction. In her explanation, Penny recognised these acts of fighting for her mother as part of her responsibility in providing the best care she could for her mum.

Mary also reported becoming more assertive when dealing with the medical system. She found that part of her role as her mother’s carer was to ask the uncomfortable questions about treatment and prognosis, and to question why certain procedures were being carried out. Mary commented:

“I’ve got to go in [during medical appointments] because mum will just sit there and then I have to ask her questions, so I say, oh do you mind if I ask questions, they mightn’t be nice but I am going to ask them.”

On a more personal level, she returned to her specialist who had performed her hysterectomy to confirm that her ovaries had been completely removed (her mother had ovarian cancer despite having a hysterectomy, which should have removed her ovaries years earlier). It is interesting that both participants recounted their increased assertion in relation to their dealings with the healthcare system, implying that there are aspects of the healthcare system that may be failing the patients and their families in terms of their psychological needs. It was also frequently noted by other participants that they often did not understand their parent’s diagnosis, and so sought information from external sources, such as the internet and the Cancer Council. This suggests that more can be done to improve interactions between the medical profession and the consumers of its care services. However further investigation looking specifically at this matter is required before firm conclusions can be drawn.
5.5.6 Cancer-related health behaviours.

Eight participants in the study mentioned engaging in some behaviour to prevent or detect cancer. Interestingly, most of the comments related to medical testing such as skin checks, pap smears, colonoscopy, and prostate checks. For some participants, that represented a change in behaviour, as they had not previously considered cancer-related testing before. For example, James reported that he now visits the doctor every six months for a check-up, and is willing to have prostate screening; however, his doctor has advised that it is not necessary at this stage. In another case, Michelle had her first mammogram after her mother was diagnosed with breast cancer. In cases where the participant was already engaging in such action before their parent’s cancer, their parent’s illness served to reinforce the value of such tests. Beth recognised that she “shouldn’t put off tests,” and Stacey, who has annual mammograms and regular colonoscopies, reflected that “my feelings about anyone having cancer is that if you suspect it go and do something the moment you can, and never feel that it is silly.”

Changes in health-related lifestyle behaviours were reported by two participants. Mary reported increased sunscreen usage, wearing a hat, and dietary changes, while Stacey reported changes in medication usage and diet. An interesting finding is that five participants suggested that lifestyle factors contributed to their parent’s cancer (e.g., stress, drinking, and smoking) and identified similar behaviours in themselves, but yet had made no attempt to alter those behaviours. For example, Karen explained that her father developed pancreatic cancer “because he was too dependent on alcohol” and “he drank like a fish.” She later reported that she has questioned whether she displayed similar tendencies, and whether that meant she would get the same sorts of illnesses, but confessed “it doesn’t stop me from having wine but it makes you wonder.”

5.6 Experience Intensity

The focus of this chapter now turns to an examination of the negative themes describing the experience of parental cancer (see Figure 5.2). The most prevalent negative theme was experience intensity, which is
defined as the emotional and cognitive reactions and appraisals of the adult child in response to their parent’s cancer. This theme includes data that relates to both an initial reaction at time of diagnosis, as well as the changing impact at all stages of disease progression. While the findings of the current study suggested that positive outcomes in the form of benefit finding may arise, the data in this theme clearly demonstrated that no participant viewed their experience as a universally positive occurrence. Rather, the stories that were shared seemed to imply that, although some positive outcomes had emerged, it was still a time of intense struggle, emotional upheaval, and change. The theme of experience intensity was mentioned to some degree by all of the 11 participants, which suggests that it is unlikely that individuals go through the experience of parental cancer without evaluating the emotional impact and subsequent level of change that emerged as a result of their parent’s illness. The three sub-themes were: (a) impact of parental cancer; (b) emotionally difficult times; and (c) isolation.

5.6.1 Impact of parental cancer.

For six of the 11 participants the impact of the diagnosis and treatment of parental cancer was very intense, and created huge deviations from their routine and life plans. Dean described the impact of his mother’s cancer as “the biggest thing in my life, especially the last few weeks, they were just dreadful.” This is an insightful comment, as Dean was a successful professional with a young family and international career; however, he still evaluated his mother’s cancer as the most significant life event he had experienced to date. Similar sentiments were expressed by Penny, who described it as “probably the most difficult thing I have ever had to go through,” and Gina who stated “it was this huge adjustment in a very, very short time.” Statements such as these provide some insight into the magnitude of the changes that the adult child faces, when a parent is ill with cancer.

Another key aspect of this sub-theme was that some participants felt an intense need to be close to their parents, taking on quite a protective role. For example, James cancelled all work-related travel, so that he could visit his father on weekends. James recognised that such changes were not
necessary, as his father was not terminally ill, but summarised it as "it is not that there is a need for me to stay close to home, I just don't feel comfortable going away." In another case, Karen travelled to be with her father once he was hospitalised, refusing to accept her mother’s assurances that her father was OK. Karen stated:

She rang me back that day and said he has gone to hospital, I said I’m over the next day, she said no its fine, he’ll be okay and I said no I’m over the next day, and I got there on the Monday and he died on the Wednesday.

For three participants, the impact and resulting changes were so intense that their lives became quite enmeshed with their parents to the point where they would refer to themselves as the patient (e.g., “So I am still up to the second last of the hormone needles at the moment,” James), or use collective pronouns, such as ‘we’ and ‘these,’ to tie parent and child together (e.g., “...it’s one of the most important things that you say through all the best palliative care ... let the patients have some control, but when these patients [referring to herself and her father] took control the medical staff didn’t like it at all,” Sally).

Intense impact, however, was not a universal phenomenon, as other participants reported being able to get on with their life with minimal disruption. For example, when asked about the impact of parental cancer, Beth stated “probably not a huge impact, I mean I am still doing what I want to do I guess. It makes things harder but as a big impact probably not so much.” A second participant was able to recognise that the disease had the potential to disrupt her life, but that she had “come off fairly lightly because my mother is a very positive person and hasn’t pushed the burden onto other people” (Michelle).

5.6.2 Emotionally difficult times.

The participants reported a range of emotional reactions that were changeable as the disease progressed. Indeed, Beth described her journey as an “emotional rollercoaster [filled with] frustration, sometimes angry, sometimes just really sad.” Reported emotions included shock (e.g., “I didn’t know that it would happen to us,” Mary), anger (e.g., “my workplace
was very sympathetic and supportive, but people would say things and I would get so angry and I realised eventually that... sometimes it didn’t matter what anyone said,” Penny), uncertainty (e.g., “…for me at different times a sense of when will this end, I wish it would end either way in some ways...” Penny), frustration (e.g., “...he goes OK for a little while and then the next thing will hit, and yeah you go through that, and it’s just a matter of waiting.” Beth), and sadness (see Section 5.7).

Five of the participants struggled with feelings of guilt, which arose due to their wishing the experience would be over, due to care issues, or due to perceived inappropriate reactions on their behalf. For example, Beth, whose father’s leukaemia was marked by unpredictable periods of stability and decline, described how this pattern made it difficult to plan her own life, and commented “You get frustrated, then you feel, sometimes you wish that he wouldn’t get better, that it would just be better if it were all over, and then you feel guilty for feeling like that, I guess helpless.” In contrast, Penny reported feeling guilt surrounding issues relating to her mother’s care, particularly as she perceived her father as providing inadequate care, but, due to her problematic relationship with him, she had not intervened. Penny reflected:

When she went home as well I sensed that dad wasn’t looking after her, I think he met her physical needs but he wasn’t very good at nurturing or comforting her, so it was frustrating and I felt guilty about not ensuring that things were right.

A final example is Michelle, who acknowledged that she had been relatively unaffected by her mother’s cancer, but recognised that, for her mother, the disease had been a significant episode in her life. Michelle was disturbed by this discrepancy, and reflected “...this is a major trauma in my mother’s life and I probably haven’t felt it as much as I should.”

It is notable that four of the participants described their parent’s cancer as a traumatic experience. For Gina, the experience of having both parents diagnosed with cancer within 18 months of each other was described as being “really quite traumatic.” Cathy found that people’s enquiries into her welfare served as a reminder of the “traumatic situation” she faced,
while Dean stated that “I went through a bit of a crisis.” Additionally, Penny commented that she believed her search for meaning as to why her mother got cancer represented a traumatic coping reaction. Penny stated “I was just aware that to move through it I had to find meaning of some sort because that is just a trauma response.” It is, however, noted that one participant, Michelle, did not view her experience as a trauma, noting that she had coped by keeping her emotions and imagination in check. Michelle stated “I was just kind of wait and see, I just haven’t traumatised myself too much by the what ifs.”

5.6.3 Isolation.

The final sub-theme of the experience intensity theme is isolation, which was reported by two participants. In Stacey’s situation (an only child who had already lost her father), she recognised that, with her mother sick and her extended family focused on her mother’s condition, there was no one there to support her. Stacey commented that the hardest thing about her experience was “not having anyone, it was the only time in my entire life; both before and since, that I wished that I had a brother or a sister, the only time. There was no one.” In contrast, Mary who is from a large family and is married with her own child, also reported finding the situation very isolating. Heavily involved in the care of her mother, Mary reported facing significant stress and challenges, often placed in situations that she was uncomfortable in (e.g., asking doctors the tough questions, overseeing her parent’s financial matters). While Mary stated that she is happy to look after her mother, she also commented that it is assumed that she will be able to handle it all, and that has made her feel neglected and invisible to her siblings. As Mary stated, “I’ve only had one sibling ask me how I am ... and I said to her do you realise that is the first time in five years that anyone has asked me how I am going?” These two different examples highlight how lonely and separated adult offspring can feel as they go through the experience of parental cancer.

5.7 Grief and Loss

The second negative theme to emerge from the data was grief and loss, which encompasses various aspects of the sadness and misery
associated with parental cancer, while acknowledging that cancer has the potential to irreversibly alter the adult child’s sense of security and change one of the individual’s primary attachments. Importantly, this theme was present in participants who had lost their parents, participants whose parents were currently undergoing treatment, and in participants whose parents had fully recovered, suggesting that the grieving process is present at all stages of the experience of parental cancer. The grief and loss theme is present in the stories of nine of the 11 participants, and is comprised of two subthemes: (a) cancer-related losses; and (b) witnessing suffering.

5.7.1 Cancer-related losses.

Seven of the 11 participants discussed losses they had experienced as a direct result of their parent having cancer. For three of the participants came the realisation that their parents were not infallible and would not live forever; this challenged their sense of security and place in the world. For example, Gina stated “I learnt that they are human, because when you see your parent, when you are young you see them as being there forever which they are not.” A similar sentiment was expressed by Mary, who said that she had held the belief that nothing could happen to her parents, until her mother was diagnosed with cancer. A consequence of this realisation was that Mary reportedly thought about death frequently, hers and that of her parents. Karen also described the moment when she realised her dad was going to die, detailing how, as she drove away from her final visit with him, she “started shaking” and said to herself “I’m never going to see my Dad again.”

A second aspect of loss that emerged from the data was that parental cancer contributed to negatively perceived changes in key relationships. This topic was mentioned by three participants, as they described changes in their relationships with their sick parent and other family members. Beth highlighted how her father’s long-term battle with leukaemia had altered her relationship with her mother, due to her mother’s care commitments. Beth described her relationship with her mother before her father’s illness as “quite close,” but that, since his health has declined, she sees her mother infrequently, as is evident from Beth’s statement of “...when he is bad Mum
can’t leave him, when he is not bad she is afraid to leave him in case something happens.” Furthermore, Beth mentioned that this lack of contact had also impacted on her children’s relationship with their grandparents. Prior to his illness, Beth’s parents came to visit regularly and were “fairly involved with them [the grandchildren].” To demonstrate the change in this relationship, Beth described how she had to explain to her daughter that grandma and grandpa were not able to come to her grandparents’ day at preschool because “granddad is too sick.” Beth summarised these changes as “frustrating,” and expressed that, if she could change one aspect of this experience, it would be that, as she felt that she had “lost both of them for this time.” Beth also described other cancer-related losses in her father, as he changed from a strong working father to a weak elderly man. Beth commented:

A little while ago . . . he had to go to hospital and I went to help mum and I walked in the room and it was just this little frail old man sitting on the bed and I mean he was never like that.

Similarly, Penny also reported that her loss started well before her mother’s death, as her mother changed throughout her illness. Penny outlined how her mother went into a deep depression, which Penny found “really hard” to deal with. She felt responsible for keeping her mother focussed and positive, a goal she did not believe she achieved. In addition to the depression, Penny’s mother also had a fall during her treatment, which led to a brain haemorrhage and subsequent brain damage. Penny’s grief is clearly expressed in her statement:

...from that point on ... through to early July when she died she was never herself due to the damage [caused by] that build up of blood ... so it was dealing with her being someone else for a while. She had always been really smart and good with words and she couldn’t communicate properly, she couldn’t get the right words, and that was really distressing for her and us.

Penny also described how the loss of her mother had altered the way her family interact, stating “mum was the one that held us all together and we’ve had to, I still don’t think we have found our way of being together without her.” This awkwardness is present, even though Penny has described positive changes in her relationships with her siblings, suggesting
that the void of her mother not being present at family functions is still keenly felt. This was confirmed by Penny, who reflected that she still struggles to accept her mother’s death at key times of the year. For example, Penny stated “this will be the fourth Christmas without her and it’s like that’s too many, it shouldn’t be that far along, and it is hard to deal with that day to day sometimes.”

The data provided by Beth and Penny is important, as it highlights that grief and loss may begin at any point in the experience of parental cancer, something which may be overlooked until the death of one’s parent actually occurs. For these two participants, their grieving process started well before death, indeed Beth’s father was still alive at the time of the interview.

There is also evidence of the ongoing nature of grief associated with losing one’s parent. While reflecting on the loss of his mother, Dean identified that he feels a “significant gap,” which had previously been filled by his positive relationship with his mother. Dean was able to identify that this loss had contributed to personal changes, which he believed his wife would view as negative. For example, Dean stated:

I think my wife would probably say that I am not as fun as I used to be, and I think I am sadder than I used to be, and I am sure a lot of that has to do with saying goodbye to my mum.

In addition to the loss of relationship with his mother, Dean also feels a deep regret about some treatment decisions that were made in relation to his mother’s care. As a scientist, who had worked in a related field, Dean was aware of research trials and treatment opportunities that his mother may have been eligible for. However, he was unable to get her involved due to logistical matters. At the time of the interview, six years after his mother’s passing, Dean acknowledged his unresolved grief stating “I don’t think I have ever really come to terms with that sort of grief, it is all sort of simmering there in the background.”
Cathy, whose loss was relatively recent, only 12 months prior to being interviewed, discussed her increased emotionality. She reported having difficult times around significant dates, such as the anniversary of her father’s death and Father’s Day. Cathy reflected:

"Father’s Day this year I went on a car trip to a concert with two good mates who are married to each other, they were arguing about you know who had rung whose father and who was spending time with whose parents or whatever and it just hit me in the guts, I felt very embarrassed because I didn’t want to be doing that [crying in front of friends], you know it was just, you do that and people feel that they should feel sorry for you and I don’t want them to feel sorry for me, I don’t need to be felt sorry for, I’m doing OK, this has just hit me from nowhere, . . . you know I wasn’t in that headspace and then suddenly I was.

Cathy also reported that she was easily moved to tears by certain pieces of music, news items, and examples of parent-child interactions that she observed. Cathy expressed the vulnerability she felt, regarding the emotional demonstration of her grief, when she described it as: “it is like someone catching you in the altogether sort of thing, it’s a nakedness you just don’t need to show people.”

5.7.2 Witnessing suffering.

The second sub-theme of the grief and loss theme was witnessing suffering, which was reported by four participants. Interestingly, all four participants had lost their parent to cancer and, therefore, there may be some suggestion that watching a parent go through the final stages of cancer is particularly painful and distressing. For example, Dean was unwilling to discuss the details of his mother’s final weeks, but described them as “just dreadful” and that it was exposure to “human suffering on a very personal level.” The impact this has had on Dean is evident in his altered view on euthanasia, with Dean stating “you know I am a firm believer in euthanasia now because I certainly wouldn’t want anyone else to have to go through that if they could possibly avoid it.”

Penny also found the final weeks of her mother’s illness very difficult, especially as she and her siblings had to make the decision to terminate their mother’s treatment. As is evident in the passage below,
Penny discussed how the siblings originally planned to keep the decision from their mother, but in the end she had to tell her mother:

The doctors were saying we don’t think that there is anything else we can do so then that decision to take her off the respirator ... but she wouldn’t stop breathing without it, but would be difficult for her. So they took that out and we didn’t actually tell her that that was going to happen ... on the Saturday night she just wanted to know what was going on and I ended up telling her and that was probably the most difficult thing, saying this is what’s happening and this is the decision ... but after telling her she went very calm and shut her eyes so I think I did the right thing.

As Penny recounted her story, she often started sentences with “the most difficult part ...” and “the hardest thing was. . .”, which indicated that there were many aspects of her experience with parental cancer that were difficult to go through and adjust to. Penny identified this pattern in her speech, and commented “as I keep talking I kind of think that was the worst and then no the next thing’s the worst.” The recounts provided by Dean and Penny provided some insight into the dreadfulness and suffering that the adult child may witness, when their parent dies from cancer.

Importantly, bearing witness to the passing of one’s parent was not viewed as universally negative. Sally was called to the hospital when her father was dying, and she described the situation as being able to “talk him through it [death],” calming him down from an agitated state. Sally seemed proud that she had been able to be there for her father at such a critical time, and expressed that she hoped someone would be there for her. In another example, Karen described how watching her father pass away helped her to get over her fear of death, and helped with her adjustment to her loss. Karen stated:

I arrived there, I watched him die, I realised that it wasn’t really that bad, I was sitting there dreading it because the only thing I knew about death I had seen on the TV, I had never seen anyone dead before so I am watching him and I am counting his breaths as he was slowly slowing down ... and as he died I went oh ok he is not there anymore and it wasn’t bad, and that sort of overcame some of the fear, I mean even though you want to know where he is and what has happened, it overcame some of that, the horror of death.
5.8 Involvement in Caregiving

The third negative theme to emerge from the data related to the individual’s involvement in caring for their sick parent. The full spectrum of involvement in care possibilities was present in the participants. Some participants reported that they were their parent’s primary carer and lived with their parent during their illness, others were very closely involved, attending medical appointments, treatment centres, and assisting in patient recovery at home, while some had minimal to no involvement in care. The involvement in caregiving theme was defined as actual and perceived changes in role and circumstances, arising from the provision of support to and contact with a parent with cancer. The sub-themes constituting the involvement in caregiving theme are (a) objective involvement in care; (b) duty; (c) the guardian; and (d) problems relating to role.

5.8.1 Objective involvement in care.

The objective involvement in care sub-theme details the changes to existing roles and/or the new roles that participants took on during their parent’s illness, which directly relate to their participation in care activities (e.g., going to doctors appointments, managing parents finances, assisting with personal care, cooking for parents). The care activities may be conducted at an individual (i.e., being the family member responsible for patient’s care needs) and/or family level (i.e., allocation of care tasks throughout family). To be considered for inclusion in this sub-theme, the participant had to identify that they clearly believed that the changes had been the direct result of their parent’s cancer. Such changes were reported by seven out of 11 participants.

It was frequently mentioned that care-related changes arose because the adult child was able to see that there was a need that was not being fulfilled, and “somebody had to do it” (Dean). For some participants, taking on care-related responsibilities provided them with a way to feel that they had some control over the situation, and so it helped with their adjustment. This is evident in the statement made by Stacey, who commented “I wanted to play nurse; I liked playing nurse so I felt I had control.” In a similar sentiment, James described how his involvement in caring for his father
provided him with a “job,” which helped him adjust to his father’s diagnosis and allowed him to feel involved. James stated: “I have to have a job, I have to know what I am doing, and once I know what it is I can just do it.” Sally also found that a sense of control regarding her Dad’s treatment assisted in her adjustment to the experience, as is evidenced by her statement:

It [the final six weeks] wasn’t just a runaway train, you weren’t just a passenger, we were able to do what we thought was in our power to do, to have the situation run the way we wanted it to. We couldn’t stop that [his dying], but at least we could stage manage it and that has been a very good experience for the family.

Another aspect of objective involvement in care is that three of the participants became the family communications point responsible for telling people of their parent’s diagnosis, and then keeping them informed throughout the illness. For Mary, this role developed when her parents did not want to inform any of her siblings of her mother’s illness, while Karen saw her father’s decline and tried to warn her siblings of what was happening. Karen reflected that this role “changed the whole dynamic of the relationships with my siblings who didn’t really want to hear what I was saying.” As a result of adopting this new role, Karen feels she has become the family organiser, who is responsible for noting things relating to family and telling others. Dean and Mary also described how, throughout their parent’s illness, their families turned to them for information. Dean, with his history in oncology research, felt that his mother and family turned to him to help them understand what was going, and he stated “she [his mother] didn’t really know what was going on ... and the rest of my family pretty much looked to me to tell them what was going on.” Mary detailed how her mother’s cancer made her siblings uncomfortable, and how her siblings relied on her to assist them with their relationship with her mother. Mary commented “they all look at me now to be the one to tell them, I mean what they should do, how they should approach her, what they should be doing ...”

Three participants also reported that they have developed additional roles within the family, as a result of their parent’s cancer. Gina described
how she felt she had become the family matriarch, even though her mother was still alive and she was not the eldest daughter. Gina stated, “I have taken on the matriarchal support role, not that I want it, it just seems to evolve that way.” She perceived her main function in this role as “having to be very supportive” to both her parents and extended family. In addition, Gina also perceived that she was viewed by her family as the family psychologist, the person they often turn to when they are in need of answers. Cathy, who was living away from home during her father’s illness, perceived that her role was to provide some relief from the everyday worries during her regular phone calls and visits home. To achieve this, Cathy came up with the concept of “t-shirt stories” which she explained as

So I’m talking to you two to three times a week but nothing that momentous has happened to me in the last two or three days, but I went shopping and I bought this really great t-shirt on special, or I saw this kind of bird or whatever. It is making interesting stories out of little things that happen especially if they are happening in a different place.

James reported that he believed he had become an advocate for men’s health issues with his brothers, encouraging them to visit the doctor and talk about cancer-related issues. He described their existing attitude to their health as “stupid,” and that encouraging them to take their health more seriously had been “quite a task.”

It is important to note that some of the role changes that emerged during this time have had significant longevity, continuing beyond the death of the cancer patient. For example, Karen is now involved in the care of her ageing mother (the healthy parent), recently being responsible for her change of residence. In addition, Stacey and Sally both reported that their parents have lived with them at some stage since their diagnosis.

5.8.2 Duty.

For nine of the 11 participants, their involvement in their parent’s care was often expressed as arising from a sense of obligation or duty to their parent. Sentiments such as “somebody had to do it” (Dean), “someone had to stay” (Stacey), “having to take the responsibility” (Gina), “doing the right thing” (James), “something I had to do” (Penny), and “I’m the one
who has to” (Mary) were frequently expressed at various points during the interviews, indicating that many participants felt that there was no option, other than taking on the role of responsibility that they adopted. Sally described the advice of medical staff to put her mother in the hospital as “the living end,” and believed that such a decision would have been devastating for her healthy father. Instead, Sally talked proudly of her ability to keep her mother at home, and provide “a very, very nice palliative care” to her mother. Even for participants, such as Michelle, who was not actively involved in her mother’s care, there was still a sense of duty, as is evident by her comment, that since her mother’s illness, she has been “more vigilant about contacting her and making the, checking on her and those sorts of things.”

Some participants appeared conflicted about this sense of duty and the impact it had on their life. For example, James spent considerable time during the interview explaining why he was the child most involved in his father’s care, offering explanations such as still being at home when the diagnosis was made, being the only family member without children of his own, and that his family had contributed a lot to his career, so it was time to give back to them. He also stated on numerous occasions that he was “perfectly happy” to be involved in his father’s care. However, he later described his involvement as a burden, as seen in the following comment:

I was still living at home even though I was working so a lot of the burden, not burden but the responsibility for help, my mum did not deal with this very well at all so a lot of the treatment was up to me to take Dad to.

The quick correction that James makes, combined with the numerous explanations he proposes for his involvement, may indicate that he is trying to put a positive spin on his involvement in his father’s care, even though it is taking an emotional toll on him. A similar exchange also occurred in the interview with Karen and is outlined in Section 5.3.2.

It is important to acknowledge that this sense of duty to be involved in caregiving was not present in all participants. For example, Cathy argued that putting her life on hold for the duration of her father’s illness would
have violated his wishes for her, as she had recently commenced a study scholarship. Cathy did assist in the care of her father when she could (e.g. during summer holidays), however she explained her decision to continue to actively pursue her goals as follows:

In that sense you owe it to that person not to let your life be disrupted, it is a courtesy to them because they shouldn’t have to feel guilty, it is not something that they asked for, it was never all about them before so why should it be all about them now, OK they have special needs and that needs to be allowed for and that will take time and effort and emotional energy, but it is a bit rude to a person to make them your all, it puts an obligation on them that they just don’t need.

5.8.3 The guardian.

For five of the participants, there was a sense of becoming completely responsible for their parents, in essence experiencing a role reversal from being the child to becoming the parent. This was expressed in phrases such as “I find myself being the parent sometimes” (Karen), “I saw it as my role to look after her” (Dean), “I can protect her” (Mary), and “I wanted to ... fight for her in some ways” (Penny). Taking on the role of guardian was also associated with a sense of being in control. For example, Dean described that he felt like “mother hen, kind of pushing everyone around,” James “controlled when people came and when they went,” and Mary monitored visitor’s access to her mother and influenced their interactions through “control[ing] emotions around her, telling people just don’t go up there and cry in front of her...”

Another aspect of the guardian sub-theme is that the adult children frequently found themselves in situations where they were telling their parents what to do. James recounted occasions when he had to order his father to rest, and discussed the ongoing argument they had over his father’s continued smoking habit. In another example, Mary detailed how she kept track of her mother’s medical appointments, controlled her parents’ finances, and how she had to teach her Dad many activities of basic living so he could live independently, while his wife was in hospital. Mary also recounted that she has taken an assertive role with the medical professionals her mother sees, believing that if she did not attend appointments, her parents would ask no questions about her mother’s condition. Finally,
Stacey reported on her mother’s present reluctance and refusal to seek medical care for any ailment, in case cancer is diagnosed. In these situations, Stacey felt that had to “shove her off to the doctor and tell her don’t be stupid.” There was the sense that Stacey found these situations frustrating, especially as her mother’s cancer has had the opposite effect on her, as Stacey reported that she has a tendency to overreact to ailments, frequently saw her doctor, and has regular tests performed for early cancer detection. Stacey commented “my husband will tell you that if I get a headache I have a brain tumour,” and that “I have gone to the doctor with that many breast lumps it is not funny.”

5.8.4 Problems relating to role.

While some participants reported being content in their new roles, six of the 11 participants reported that their new roles had created some level of tension or discomfort in their life. When asked directly how she felt about the role changes, Mary replied “I don’t like it, I don’t like it.” Expressing a similar sentiment, Karen described feeling like she was parenting her mother as “horrible,” stated that she “resented” her role, and expressed a desire for it to end. Finally, Gina reflected on her position as the family matriarch and acknowledged it was not a role she has sought.

One of the factors that may have contributed to such role frustration is that it appears that there was typically very little negotiation and communication with other family members about which roles and responsibilities were to be fulfilled by whom. Indeed, only two participants (Penny and Sally) indicated that such issues were even discussed. The problems that arose from this lack of communication manifested itself in three main ways: (a) resentment towards siblings; (b) anger and frustration towards the healthy parent; and (c) tension in relationships with their own spouse and/or children. Additionally, three participants reported the presence of two problems, namely resentment towards siblings or healthy parent coupled with tension in the relationship with one’s own spouse and/or children. One explanation of this pattern is that the additional role of caring for their sick parent placed substantial strain on the relationships with their spouse and/or children, which in turn created a feeling of resentment.
towards one’s siblings or healthy parent, whom they believed should be more involved.

Resentment towards siblings was reported by three participants, who typically felt that their siblings did not do enough to support them and/or their parent/s. Karen reflected on her ongoing support for her mother, and how she was required to point out the issues regarding her mother’s ageing to her siblings, who she perceived as unwilling to “take any responsibility or think about it.” Furthermore, Karen discussed how she felt her siblings expected her to fulfil this role, but then criticized how she went about fulfilling it, as is evident in her statement, “I think they all expect that I'll look after mum and organise things and if anything needs to be done I'll do it, and then they whinge that I am bossy.”

Birth order may play some role in how the participants perceived their role, and the role their other siblings should have taken. For example, Karen, while discontented with her position reported a sense of acceptance as she was the eldest daughter, as is evident in her statement: “I'm the middle child but the eldest daughter and in some way I intuitively knew that this [role change] was happening.” On the other hand, Gina, the third of four daughters, believed that her eldest sister should have taken on the role of family matriarch. Similarly, Mary described herself as “the baby” of the family, and was openly critical of her siblings who she perceived as being unwilling to be involved. For example, Mary commented:

*I have even suggested to other members of the family to take her so that they don't think that I am occupying the whole thing and they [say] oh no, no, no you're right, but sometimes, I mean sometimes I tell them that I have a meeting at work, I just can't take her and they have said, oh we can't either.*

Mary was also concerned about how her siblings would perceive her involvement in her parent’s finances, and so she had decided to keep that aspect of her care a secret from them.

Anger and frustration towards the healthy parent was reported by two participants. Penny struggled to deal with her Dad, who had substance
abuse issues at the time. Her father’s addictions led her mother to ask her to care for her father, and she reflected that “I don’t think we [her and her siblings] did a very good job on that ... and also we didn’t want to have to [look after him].” Penny remained angry and resentful towards her father, who refused to work in with the family’s roster of visitation shifts, and whose substance abuse she described as him “not giving mum his best.” When reflecting back on her experience, Penny reported that she continued to feel guilt and regret that she had not monitored her mother’s home situation more closely.

Dean also reported anger at his father, who had left his mother several years prior to her illness. While his father did return to the family during the cancer episode, Dean perceived that his father did very little to assist in his mother’s care, and subsequently he spent large quantities of time at his mother’s home ensuring her needs were met. When asked what his current relationship was like with his father, Dean stated “I don’t make the same effort as I would have done before for him.”

The final problem associated with role that was identified by three of the participants was tension in the relationship with their spouse and/or own children. This issue was exemplified by Dean, who acknowledged that his caring responsibilities impacted on his relationship with his wife and children. Dean commented that “[caring] has always come fairly naturally to me but I detected that it was becoming a bit of a problem for my own family.” While Dean recognised that he had neglected his family during his mother’s illness, there was also evidence that this issue continued to impact on his relationship with his wife. For example, Dean stated “they [his wife and children] were neglected to some extent because I was having to do so much for my mum, and you know it still comes up as a topic of conversation.”

The notion of having to choose between one’s parents and one’s own family also emerged in the cases of Karen and Mary. Karen identified herself as “that sandwich person,” who is torn between responsibilities to parents and children, a position that she resented. Mary described how her
intense involvement in her mother’s care meant that she had to “just leave my husband and son,” telling them “you guys are on your own, go for it.” In the cases of these women, both felt strong anger and resentment towards their siblings, who they felt were not contributing to looking after their parent, but were content to leave the burden of care up to others. This suggests that, when a family is able to work together in providing care, the perceived stress and burden associated with the role may be reduced, as was the case with Penny and Sally. However, when one family member is left to do the majority of the caring, it can create tensions in their own family, and adds to the stress associated with their parent’s illness.

5.9 Discussion of Themes

The interviews provided valuable insight into the experience of parental cancer, thereby enhancing the understanding of an under-investigated area in cancer research. Perceived benefit finding was reported in a range of areas by participants, suggesting that positive outcomes may arise across various qualitative domains, thereby fulfilling the first research aim. The four main areas of benefits identified in Study One included: (a) a transformed relationship with the sick parent; (b) family matters; (c) altered life priorities; and (d) personal development. Benefits relating to personal relationships, family, and altered life outlook were reported more regularly, and appeared to be perceived as more important to participants than benefits relating to personal development9. The finding of perceived benefits in the adult children of cancer patients challenges the narrow focus of cancer-related research, which has tended to focus exclusively on the range of psychopathology that may arise from parental cancer. While difficulties (i.e., the three negative themes) were evident, benefit finding was also clearly outlined by all 11 participants, highlighting a clearly overlooked outcome of cancer on families. It is suggested that research examining only

9 The author recognises that making comparisons, such as those in the text above, may be viewed as problematic, as it may represent quantitative comparisons of frequency and mean. However, throughout the interviews, the author felt that, when personal development benefits were mentioned, they tended to be discussed in less detail, and often only emerged with direct questioning or prompting. In comparison, benefits relating to the sick parent, family, and altered life priorities were spontaneously generated by the participants, discussed in detail, often with multiple examples given by participants to demonstrate the change. From this observation, the author has concluded that personal development themes may arise, but that they appear to be less salient to participants, compared to the other benefits that they mention.
negative psychological outcomes limits our understanding of the parental cancer experience by failing to acknowledge potential positive outcomes. Importantly, the findings of Study One highlight clear areas of benefit finding, thereby expanding research knowledge in this area of investigation.

The data also revealed some of the strains arising from having a parent with cancer, and broadened our understanding of the range of emotions that the individual may feel. The three themes relating to the experience of parental cancer identified in Study One were: (a) experience intensity; (b) grief and loss; and (c) involvement in caregiving. The inclusion of these themes is crucial, as they highlight that parental cancer may be a highly stressful event, and this finding supports the contention by Rait and Lederberg (1990) who argue that cancer affects the entire family unit. Furthermore, there is evidence that a small number of participants described their experience as traumatic, supporting the contention that the broader definition of trauma as proposed by Calhoun and Tedecshi (1999) may be relevant to this experience.

The following sections outline the current findings in relation to the empirical and theoretical literatures. Section 5.9.1 summarises the current findings in relation to research studies based on samples of cancer patients, spouses and family members, highlighting similarities but also identifying key points of difference. Section 5.9.2 examines how the data obtained in Study One fits within the theoretical field of posttraumatic growth. Section 5.9.3 summarises the findings of the negative themes, and discusses their support of theoretical and empirical knowledge. Section 5.9.4 examines the pattern that emerged between the benefit and negative themes in Study One, suggesting that the themes interact and that the negative themes may be critical for the emergence of benefit finding. Finally, Section 5.9.5 identifies the limitations of the current study, and proposes ways these limitations can be addressed.
5.9.1 Summary of benefit finding themes in relation to empirical literature.

Overall, the content of the theme *transforming the relationship with the sick parent* suggest that a perceived improvement in the relationship between adult child and sick parent is a possible outcome for both genders amongst a range of cancer diagnoses. Such a finding mirrors the results of several qualitative and quantitative studies conducted on the spouses of cancer patients, which suggest that cancer has the potential to transform close family relationships. Specifically, Weiss (2004) reported that breast cancer couples reported spending more time together, while Dorval et al. (2005) and Winterling et al. (2004) found that most couples perceived that cancer had brought them closer together. Similarly, Hilton et al. (2000) described how cancer couples put an effort into creating special time together. Comparable sentiments are expressed in the current study. For example, James described spending more leisure time together with his father, while Mary and Michelle described getting closer to their ill mothers. In considering the qualitative works on parental cancer, five (33%) of the cases presented by Oktay (2005) and six (37%) of the cases presented by Tarkan (1999) provide evidence of enhanced mother-daughter relationships among breast cancer patients and their adult daughters. In considering the combined literature on children, spouses and the current findings, it appears that parental cancer may serve as a catalyst for positive changes in parent-child relationships.

Participants in the current study also highlighted that they viewed parental cancer as a catalyst to help resolve previous conflicts and issues between the parent and child. The cases of James and Cathy both provide evidence that cancer changed the emphasis in the parent-child relationship and for some, allowed old issues to be worked through or overlooked, creating a new way for parent and child to connect. This finding is supported by the research by Baxandall and Reddy (1993) and Tarkan (1999), who both present case examples of how cancer can resolve conflicts in parent-child relationships. The transformation of the relationship between James, Cathy and their fathers can also been seen as reflecting the finding of Keitel et al. (1990) that cancer provides a ‘lens’ to shift focus from the
trivial aspects of relationships, and allow individuals to put more energy into establishing a new way of interacting.

An interesting finding to emerge was that some participants (i.e., Sally and Dean) reported increased respect for their parents in relation to how their parent dealt with their illness. This finding may be especially important, as it suggests that the experience of parental cancer may provide the adult child with a primary role model of illness behaviours. The parental role model may provide examples of both positive (e.g., handling cancer with dignity) and negative behaviours (e.g., keeping the illness a secret) that the child may either later demonstrate or try to minimise, when facing similar health situations. For example, Sally was proud of the dignity that her mother showed during her battle with breast cancer, yet critical of her decision to hide the disease from her family. The suggestion that parental illness behaviours may serve as role models for their offspring is supported by studies which have demonstrated that specific illness behaviours are learned through familial modelling, and can influence overall physical and psychosocial adjustment to illness (Elfant, Gall, & Perlmutter, 1999; Levy, Whitehead, Von Korff, & Feld, 2000). This concept is identified as a potentially important area for future research.

The perceived benefits identified in the family matters theme reflect three concepts, namely improved familial relationships, increased valuing of family, and a consideration of future family ties. Such themes are present in the findings of other studies and, in her review of cancer patients, Thornton (2002) identified studies that have reported benefits, such as spending more time with family, improved relationships with siblings and children, and an increased emphasis on family, all of which are present in the current study. The study by Hilton et al. (2000) supports the current finding, as the researchers found that spending time with family and “slow[ing] down to enjoy family life” (p. 446) were sentiments that emerged in their sample of breast cancer spouses. In the scant literature on adult children, Leedham and Meyerowitz (1999) found that adult daughters reported increased closeness in family relationships and improved communication within the family to be positive outcomes arising from parental cancer. An increased
emphasis on family is also present in the data detailed in seven (47%) of the cases presented by Oktay (2005), and in one (6%) case by Tarkan (1999), usually reflecting improved relationships with the healthy parent. As such, the current findings add to the emerging evidence that parental cancer can impact positively on family dynamics and the perceived value of family.

It is important to acknowledge that positive changes in the arena of family are not a guaranteed outcome from parental cancer, and there are studies that find the opposite pattern of findings. For example, Curbow, Legro, Baker, Wingard and Somerfield (1993) found that 8% of their sample of bone marrow transplant patients reported negative changes in their relationships with family members. A similar result was found in the current study. For example, Penny and Dean reported anger towards their fathers, while Mary and Karen reported resentment towards their siblings. Taken together, these two findings suggest that negative relational changes may arise; however, they appear to do so less frequently than positive changes in relationships.

The current study also suggests that parental cancer may prompt adult children without children of their own to consider starting a family. The cases of James and Cathy (the only two unmarried and childless participants) both reflected that their parents’ cancer had led them to reflect upon having children, although their motivations were different. James, whose father was still alive, wanted to start a family so that his children could know their grandfather, while Cathy, who had lost her father, reported increased recognition regarding the importance of family ties. In their respective studies of daughters of breast cancer patients, Oktay (2005) and Tarkan (1999) report similar findings, with some of their participants going to great lengths (e.g., video histories, journaling, writing family histories) to ensure that unborn children will have some connection with their ill or deceased grandmother.

Overall, the combined themes of transformed relationship with the sick parent and family matters were the most frequently mentioned and detailed areas of perceived benefit finding in Study One. Participants were
able to provide detailed descriptions of how relationships had changed, and reflected the sentiment that parental cancer allowed them to recognise that family is an important priority in their life. This finding supports the conclusion drawn by Thornton (2002), who found that the majority of cancer patients reported positive transformations in familial relationships.

The benefits identified in the altered life priorities theme reflect both attitudinal changes (e.g., valuing interpersonal relationships) and concrete behavioural changes (e.g., changes to work patterns, increased participation in leisure activities). The finding that parental cancer may lead to a reappraisal of life goals and activities is similar to findings of spouse studies, such as Germino et al. (1995) and Gray et al. (2000) who found that spouses often reassessed their work and leisure options during the cancer experience. Mellon (2002) reported a changed outlook on life in both cancer survivors and family members, typically expressed as not putting things off and making the best out of life. Furthermore, the theme of altered life priorities is clearly evident in the adult daughters represented in the qualitative work of Oktay (53% of cases) and Tarkan (37% of cases), who report changes to work and career, and an increased involvement in voluntary and cancer advocacy work. Taken together, these findings and the data obtained through the present study do suggest that a changed outlook on life and a restructuring of priorities is a potential beneficial outcome arising from parental cancer.

The final benefit related theme was personal development, reflecting perceived changes to personal qualities and positive changes to health behaviours. There were some notable differences between the themes that arose in the present data and the personal development concepts found in other studies. For example, Thornton (2002) cites studies of cancer patients, which found increased self-worth, taking more time for self, improved self-image and increased satisfaction with life accomplishments as representing benefits associated with the self. These themes are notably absent from the accounts of the participants in the current study. There are also some differences between the present findings and the benefits reported in Oktay (2005, personal development themes present in 53% of cases). For example,
Oktay found evidence of increased self-worth and taking time for self, themes that are not present in this study. Additionally, there was a stronger emphasis on changes to health behaviours, with participants in the Oktay study consciously choosing healthier lifestyle options, such as exercise, stress reduction and dietary changes. While there is some evidence of health behaviour change in the current sample, the main focus is on medical testing to detect cancer, rather than on lifestyle behaviours that may help to prevent the disease. There is also an example within Study One in which a participant identified a potential lifestyle link for their parent’s cancer, yet reported that she continued to engage in that behaviour herself. The health behaviour changes in the present study are more consistent with the Tarkan (1999) data, with two cases in Tarkan’s study discussing increased medical testing for cancer detection and zero cases mentioning lifestyle factors. However, the Tarkan data relates to genetic screening, and this was not mentioned by any of the participants in the current study. Such discrepancies between the studies may reflect real differences between the populations, or may be related to methodology and the type of questions asked during the interviews. An alternate explanation may be that it is easier for the adult children to schedule a screening test than to make the required lifestyle changes. Having the test provides reassurance and peace of mind in a relatively short time, while lifestyle change would require ongoing effort and commitment. This is identified as an area requiring further investigation.

It is also important to note that the theme of personal development was substantially less prevalent (i.e., mentioned less frequently, discussed in less detail) in the data in comparison to the other themes (see footnote on page 130). There are several potential explanations for this difference in emphasis, including that, with the illness being present in one’s parent, the individual’s attention is directed externally towards others, therefore reducing introspective self-reflection which may give rise to benefits, such as increased self-worth and enhanced self-image. Alternatively, parental cancer may add to the workload of adult children, as they attempt to balance work, care, their own family and other activities, such as study and leisure. Consequently, the adult child may be ‘time poor,’ and therefore does not
have the opportunity to engage in activities that enhance personal
development, while simultaneously finding that they have reduced
opportunities to take time out for themselves. Another possible explanation
is that absence of such themes in the current data may be a by-product of the
small sample size, and therefore further investigation with a larger sample
size may provide greater insight into this area.

5.9.2 Summary of benefit finding themes in relation to
theoretical concepts.

The types of perceived benefits reported in Study One mirror the
classification of growth domains proposed by Tedeschi and Calhoun (1995)
and Thornton (2002). Both Tedeschi and Calhoun, and Thornton proposed
that growth occurs in the areas of self-perception, interpersonal relationships
and life perspective. In considering the themes that emerged in Study One,
clearly the themes of *transforming the relationship with the sick parent* and
*family matters* fit within the growth category of interpersonal relationships,
while *personal development* matches the category of growth associated with
self-perception. The theme of *altered life priorities* mainly fits within the
category of growth relating to life perspective, however the sub-theme of
valuing people and relationships is best conceptualised as falling within the
growth category of interpersonal relationships. It is therefore evident that
the theoretical categories of growth proposed by Tedeschi and Calhoun, and
confirmed by empirical work by Thornton, are also highly applicable to the
types of benefits being reported by adults whose parents have cancer,
thereby addressing the second aim of Study One.

Many of the types of benefits reported in Study One provide support
for the contention that posttraumatic growth represents an outcome (or
construction) of the trauma experience (Tedeschi & Calhoun, 2004;
Zoellner & Maercker, 2006). For example, James’ reported increase in
leisure activities with his father, Mary’s reported change in her behaviour
relating to skin cancer prevention, and Karen’s move to establish her dream
rural property, are all evidence of positive growth outcomes that could be
confirmed by observation. More subtle examples of growth outcomes are
evident in the cases of Penny, who reported an enhanced sense of closeness
to her siblings, in Dean’s decreased intensity for work, and in Cathy’s increased sense of compassion for others.

However, there is also some evidence to support the notion that posttraumatic growth may reflect a coping strategy, in the form of positive illusions. For example, Stacey reported that caring for her mother gave her a sense of control, which Taylor (1983) would interpret as an attempt to establish control over the situation. Several other participants also reported taking on the role of parental guardian (see Section 5.8.3), which allowed them to establish some control over care-related aspects of their situation. A sense of control has been associated with positive psychological adjustment in patients with a variety of diseases (see Thompson and Kyle, 2000, for further information), and the current data seems to suggest that finding an element of the parental cancer situation, which can be controlled, may play a role in coping for adult children of cancer patients. The relationship between control and coping with parental cancer is identified as an area in need of future investigation; however, it will not be explored in Study Two of this thesis.

An important case example of the possibility of growth as an illusion is present in the data from Cathy, who reported that her relationship with her father changed when he became ill, and that she liked her sick father better than her healthy father. This can be seen as a modified example of social comparison, as suggested by Taylor (1983), where Cathy had compared her perception of her father before and during cancer to find something positive in the negative. This strategy may have helped Cathy through the stress that was associated with her father’s brain cancer and subsequent death. However, it was something that Cathy showed evidence of struggling to reconcile at the time of interview (12 months after her loss). Cathy was particularly tearful during the interview, when comparing her Dad before and during illness (see Section 5.2.1), eventually stating:

*It is distressing because as much as you want to know your parents as adults, as much as you want to know that you have made your peace with someone who is not going to be around for much longer you also want to remember them well and happy and those things don’t kind of gel. I have my*
dad who I like who was sick, [and] my dad who I loved but didn’t always like all that much who was well.

Zoellner and Maercker (2006) would suggest that the evidence provided in Cathy’s case are representative of growth as an illusion, she is trying to “self-consolidate by switching losses into benefits” (p. 640), which helped her get through the acute trauma stage, but which she now finds she is forced to reconcile. It should, however, not be viewed that Cathy will not be able to report long-term benefits in this area. Rather, if she is able to engage in suitable forms of cognitive processing, she may be able to reconcile the discrepancies that she reports through a modification of her existing schemas (Janoff-Bulman, 1992; Tedeschi & Calhoun, 1995). Specifically, Cathy may need to examine the changes in her father and re-interpret them to gain meaning in the form of personal significance (Janoff-Bulman, 2004). Such a reinterpretation would involve reflecting on the value and worth to be gained from the situation (i.e., my dad and I had issues, but before his death I was granted an opportunity to get to know who he really was), rather than the negative aspects (i.e., I liked my dad more when he was sick, that makes me a horrible person). This search for meaning may, in turn, reduce the dissonance that Cathy reported at the time of interview, and allow for long-term growth (as an outcome) to be created.

In consideration of the debate regarding growth as an illusion or growth as a construction, it is evident that the current study provides support for both positions. There is clear evidence of long-term positive change, and there is also evidence of cognitive distortions, which were used to assist participants through the acutely stressful periods of cancer treatment. This supports Zoellner and Maercker’s (2006) proposal of the Janus Face model, that posttraumatic growth may actually encompass both forms of change at different time frames in the experience. The finding that growth as an illusion (in the form of control and social comparison) was present only during treatment also supports the contention that this form of growth is a coping strategy that is prevalent at the beginning of the crisis, and that longer term outcome-based growth is established over a longer period of time. However, in the light of the small sample size and the nature of the data, no firm conclusions can be drawn. Consequently, future longitudinal
studies should be conducted to explore the applicability of the Janus Face model to parental cancer in greater depth.

A final element of how the data in Study One relates to theoretical explanations of the phenomenon of posttraumatic growth is evident in the case of Gina. Gina reported a transformed outlook on life, which she developed in response to having both parents live through cancer. Gina’s statement that she was able to learn from her experience (see Section 5.4.2) provides support to the theoretical contention that growth arises through a deliberate cognitive engagement with the event, and that re-interpretation of traumatic stressors can contribute to overall acceptance of and adjustment to the event. Furthermore, Gina’s reported ability to apply what she learnt from her parents’ cancer to her own painful chronic health condition supports Janoff-Bulman’s (2004) notion that growth can take the form of psychological preparedness. This model of growth proposes that the incorporation of trauma-related knowledge into basic core beliefs leads individuals to be better prepared for future trauma through increased awareness of personal strength, and the belief that they can recover.

The third aim of Study One was to examine the data to determine whether it supported a theoretical position on posttraumatic growth. The above discussion fulfils that aim, with the suggestion that there is some support for both the position that growth is a constructed outcome of parental cancer, and also an illusory process that helps in coping with acute trauma during treatment. As such, there is support for the applicability of the Janus Face model of posttraumatic growth (Maercker & Zoellner, 2004; Zoellner & Maercker, 2006); however future studies are warranted before firm conclusions can be drawn. There is also evidence to support the contention by Janoff-Bulman (2004) that posttraumatic growth may help people be psychologically prepared for future trauma. Additional discussion of the applicability of posttraumatic growth theory to the findings in Study One is detailed in Section 5.9.3.
5.9.3 Discussion of the negative experience themes.

While the aim of Study One was to examine the adult children’s perception of benefit finding, it quickly emerged that benefit finding was only part of the story of the parental cancer journey. To ignore the emotional context, within which such reported growth occurred, would be to minimise the struggle that the participants went through to accomplish their growth, and not present the whole picture of their experience in this thesis. It is therefore argued that benefits arising from parental cancer cannot be fully examined and appreciated, unless one understands the emotional turmoil that accompanies this experience. The stories recounted by the participants provided great insight into both the positive and negative aspects of what it is like to live through parental cancer, and as such support the argument of Park (2004), who proposes that to fully comprehend how growth contributes to adjustment we must examine both positive and negative aspects of the trauma.

The themes of experience intensity and grief and loss detailed how parental cancer triggers a range of emotions, which have the potential to be overwhelming and traumatic, and therefore would fit the broad definition of trauma proposed by Calhoun and Tedeschi (1999). The language used by some participants indicated that they had evaluated the impact of their parent’s illness against other significant events in their lives, and often rated it among the most stressful. For example, Dean described it as the “biggest” event in his life,” while Penny evaluated it as the “most difficult.” The grief and loss theme also provided evidence of a variety of losses, not just dependent on whether the parent lived or died. Considering this data, it is, therefore, not surprising that family members frequently report high levels of stress and psychological disturbance. While Study One did not examine any clinical diagnostic elements, the strength of the emotional reactions support other studies, which have found family members report devastation when someone is diagnosed with cancer (Mellon, 2002), elevated levels of distress (Harrison et al., 1995), and high levels of stress (Bowman et al., 2006).
In explanation of the strong emotional reactivity in family members, other researchers have suggested that anticipatory grief, poor family communication, conflict within the family (Kissane et al., 1994), a feeling of helplessness (Bowman et al., 2006) and inadequate social support (Pitceathly & Maguire, 2003) may contribute to poor adaptation to cancer within the family unit. The data in Study One reflects some of these findings, with family conflict being reported by Penny and Karen, helplessness being reported by Beth, and Mary reporting elements of conflict, poor communication and inadequate social support. Some participants in the current study also reported on a sense of isolation, which may have exacerbated their emotional experiences, as they felt there were very few people they could turn to for support. It is, therefore, recommended that appropriate support services be developed and promoted, so that adult children may make contact with others in similar situations to increase their connection with others, and reduce their perceived isolation.

In addition to the findings of the existing literature, the data presented in the results sections demonstrate how parental cancer can challenge the adult child’s sense of stability by highlighting their parent’s vulnerability, eliciting rumination on death, and altering relationships in ways that the adult child finds particularly upsetting. The cases of Penny and Dean also demonstrate that the grieving process can be long, and that it should not be assumed that the individual is over their loss, simply because a suitable passage of time has passed. These findings have significant implications for how support agencies are to address the psychological needs of adults, whose parents have cancer. The reported emotional upheaval strengthens the argument that we must increase our understanding of how parental cancer impacts on adult children to ensure that we meet both the short and long term adjustment needs of all family members.

The theme of involvement in caregiving recognises that many adult children play an important role in the care of their sick parent. This level of involvement varied from full-time carer to very little change in pre-existing contact patterns. The central concept found in this theme is the notion of role, specifically role changes, and problems arising from such changes.
Many participants felt a great sense of duty to be involved in their parents’ care, a sentiment that echoes the argument by Logan and Spitze (1996) that adult children feel a strong sense of filial responsibility, and wish to be involved in their parent’s care. As mentioned in Section 5.9.1.2, this involvement in care often gave the adult child a sense of control, and may have helped the child adjust to the acute stressors associated with treatment and recovery (Taylor, 1983).

It is, however, also acknowledged that involvement in caregiving was associated with increased stress and conflict. Perceived inequities relating to the distribution of care within sibling networks were evident, and participants reported being in situations where they felt torn between their sick parent and their own family (i.e., spouse and child/ren). The finding of inequitable distribution of care between siblings is common, with many researchers finding that this is typical (e.g., Cicirelli, 1995; Ingersoll-Dayton, Neal, Ha, & Hammer, 2003; Suitor & Pillemer, 1996). Furthermore, Strawbridge and Wallhagen (1991) found that siblings, more involved in care, reported frustration and anger towards the other siblings, who were less involved in care for their parent. Existing studies have also consistently shown that stress associated with caregiving has a negative impact on carers. Specifically, Bookwala (2009) found that sons and daughter in long-term care situations reported reduced marital quality, while depression was reported by both short and long term carers, regardless of gender. Stephens, Townsend, Martire, and Druley (2001) found that when the demands of parent care are incompatible with other roles, carer well-being is decreased. It is, therefore, concluded that the adult child caring for a parent with cancer faces considerable stress, which presents challenges for balancing multiple life roles. The stress associated with care may be exacerbated, if there is perceived inequity within sibling networks.

5.9.4 Relationship between benefit finding and negative experience themes.

Overall, the experiential themes enhance our understanding of the struggles and challenges that face the adult children of cancer patients. However, the inclusion and examination of such themes has provided the
context in which to examine benefit finding in parental cancer, and has
allowed for the discovery of a potentially important finding. Participants,
who reported a high degree of emotional reaction (as gauged through the
experience intensity and grief and loss themes) and/or involvement in their
parent’s care, also tended to report a higher number of perceived benefits.
For example, James described a strong emotional reaction to his father’s
diagnosis, accompanied by a high degree of disruption, as he struggled to
balance care responsibilities for his father with work commitments (see data
extracts on pages 113-114, and 125). This situation was further complicated
by the geographical distance between James and his father, which required
James to travel for around four hours to be with his father on weekends and
on treatment days. However, in terms of benefit finding, James was also
able to identify 11 areas of perceived benefit (the highest of the
participants). Similarly, Penny, who was highly involved in her mother’s
care and who eventually faced the decision of whether to continue her
mother’s treatment or turn off her life support, reported eight perceived
benefits arising from her experience (see data extracts on pages 113, 115,
118, and 120-121). In contrast, Beth and Michelle both reported low
impact arising from their parent’s illness (see data extracts on page 114),
and reported four perceived beneficial changes arising in their lives, the
lowest of all participants10.

Such a relationship supports the underlying premise of posttraumatic
growth theories, which contend that higher stress is required for growth to
occur. For example, Janoff-Bulman (1985, 1992) argues that the traumatic
event must ‘shatter’ the individual’s underlying assumptions, while
analogy, in which the traumatic event must be ‘seismic’ enough to challenge
underlying beliefs. Once these underlying beliefs are shattered, the person
engages in cognitive processing to re-establish a meaningful view of the

10 As mentioned in the previous footnote, the author recognises that quantifying aspects of
qualitative data (i.e. number of benefits, level of intensity of experience) is not typical of
qualitative research, and may be viewed as inappropriate by some researchers. However,
when analysing the data, the connection between the benefit themes and the negative
themes emerged strongly. Therefore, the author has included this interpretation of the
findings, as it represents a potentially important insight into how benefits might emerge in
this cohort.
world and self, and from this process benefits may arise. The pattern to emerge in the data from Study One seems to indicate that higher levels of emotional reactivity (which may be an indication of higher levels of trauma) may lead to the shattering of assumptions, and therefore does bring forth higher levels of benefit finding.

The data also suggested that the adult child’s involvement in caring for their sick parent may contribute to the level of benefits reported. Parental cancer appears to lead to role changes for some adult children, potentially altering their position within the family, due to increased parental care needs. It is possible that the changes in role also influence the intensity of emotional response to parental cancer, as they potentially add to the stress that the individual faces, while bringing them in close contact with the illness. This increased contact with the ill parent also exposes the adult child to their parent’s suffering, therefore increasing their contact with potentially traumatic stimuli.

This finding of a potential relationship between the variables of benefit finding, emotional reaction and involvement in caregiving is of significant interest, and further investigation of it is warranted. It is the investigation of this relationship which is the foundation of Study Two, outlined in Chapter 6.

5.9.5 Study limitations.

This study is to some degree limited by the characteristics of the sample, and the methodology employed. To be eligible for participation, individuals needed to have had a parent with cancer at some point in their adult lives (i.e., post 18 years). This gives rise to two problems, first the period between the experience and the interview, and second the broad range of cancer types that were discussed. The length of time between initiation of the experience and the interview varied greatly, the longest period being 25 years, the shortest just 12 months. It might be argued that the detail of recall can be affected with the passage of time, and the types of positive changes discussed could have been influenced by other life events in the interim period. However, studies on cancer patients have indicated
that benefit finding is a long-term outcome (e.g., Carver & Antoni, 2004; Lelorain et al., 2010), and therefore the passage of time may not influence the recall of benefits.

A second limitation in regard to the sample relates to the range of cancers present. During the planning phase, the decision was made not to restrict participation based on cancer type. This decision was made to ensure the recruitment of an adequate sample size, and in an attempt to address the imbalance in the existing literature, which predominantly focuses on breast cancer. However, the range of cancer types, combined with the small sample size, might have reduced the possibility of discovering important insights into the experience of specific types of parental cancer. For instance, it is conceivable that the experience of parental brain cancer, with the associated cognitive changes, is more traumatic than other cancer types, and that this might give rise to different patterns of benefit finding. It is, however, noted that, in regard to sample size, J. A. Smith and Osborn (2003) argue that interpretive phenomenological analysis studies typically involve small samples, because of the volume of data generated and the intensive analysis undertaken. Indeed, J. A. Smith and Osborn (2003) propose that a sample size of five to six is reasonable for interpretative phenomenological studies, and therefore the current sample is large by such standards. Future investigation with larger samples, or samples of restricted cancer diagnosis, might provide a fruitful avenue for further investigation.

Another limitation of the study was that participants were interviewed only once. Consequently, it remains unknown whether the type and level of benefits reported changes over time, both during the illness experience and after the successful treatment or death of the parent. This is an area that potentially deserves attention, especially if the ability to derive benefit from parental cancer assists the individual to make meaning from the losses that they experience. Although Funk and Stajduhar (2009) argue that drawing conclusions about the family caregiving experience from interview data alone is fraught with problems, as the data represents both the individuals’ description of the experience and their coping efforts, such data still provides a promising starting point from which further investigation can
be launched. It is argued that future qualitative studies consider supplementing interview data with longitudinal methods and observational techniques to enhance the depth of understandings (Funk & Stajduhar, 2009), as such techniques would allow for more detailed examination of the benefit finding phenomenon within the adult child cohort.

In summary, this chapter details seven themes and their constituent sub-themes. Overall, the themes were divided into two broad categories, themes that represent benefit finding, and themes that described the negative aspects of the experience of having a parent with cancer. The participants reported benefits in a variety of categories including improvements in relationships, an increased valuing of family, altered life views and priorities and, to a lesser extent, personal development (meeting the first aim of the study). The reported benefits fit the classification schemes proposed by Tedeschi and Calhoun (2004) and Thornton (2002), hence meeting the second aim of the study. However, it was clear that benefits did not arise without a degree of emotional turmoil being experienced by participants, hence the development of the three negative themes. It should also be noted that the findings of this study have been published in the international peer-reviewed Qualitative Health Journal reproduced in Appendix A. The third aim of the study was to assess the applicability of the proposed theoretical models of posttraumatic growth, and the data offers support for several elements. There is a strong suggestion that higher levels of growth are reported by participants who report higher disruption to their lives (both emotionally and to daily routines), which supports the basic premise of growth theories that the event must be sufficiently challenging for growth to occur. There is also evidence to suggest that posttraumatic growth may take the form of both an illusory process and a constructed outcome, and therefore tentatively supports the Janus Face model of growth proposed by Zoellner and Maercker (2006). There is also some emerging evidence to support the notion that past growth may make individuals more psychologically prepared for future challenges through changes to their cognitive schemas. Among the findings to emerge from Study One was that the degree of benefit finding reported by participants seemed to be influenced by the emotional impact of parental cancer and/or their
involvement in caregiving to their parent. This finding is now the focus of Study Two, and the aims, hypotheses, and methodology for that study are detailed in the following chapter.
Chapter 6: Study Two Rationale and Methodology

This chapter describes a quantitative study that was conducted to investigate the major thesis aims regarding prevalence, types and predictors of perceived benefit finding, and the relationship between benefit finding and the psychological outcomes reported by the adult children of cancer patients. The chapter begins by outlining the rationale for Study Two in the light of the findings of Study One, providing a statement of the study’s aims and hypotheses. The rationale details the development of the Parental Cancer Questionnaire (PCQ), a scale developed from the qualitative data obtained in Study One. The sample characteristics are then outlined, and descriptive data are presented. The measures used in Study Two are then detailed and examined in terms of reliability and validity, with recruitment and procedural details provided in the final section.

6.1 Study Two Rationale, Aims and Hypotheses

The qualitative findings in the foregone chapter provide important information about benefit finding in the adult children of cancer patients, and suggest a relationship between benefit finding and the emotional experiences that participants live through, and/or their involvement in caregiving. The presence of such a relationship indicates that the perception of benefit finding may influence psychological adjustment in response to parental cancer. While providing great insight and depth of data, the qualitative methodology employed in Study One does not allow for the reliable measurement and quantifying of benefits, or an assessment of which variables are important in the development of benefit finding.

The themes identified do, however, suggest items that could be part of a survey instrument, which specifically assesses key elements of the parental cancer experience. The development of such a measure, and its use in a larger survey study, would allow quantitative comparisons between benefits, and an examination of the value of the benefit finding concept in relation to mental health outcomes.
An ideal second study would quantify benefits in a large sample, and track the participants at multiple time frames post parental cancer diagnosis over several years. The reality of the PhD thesis time frame and requirements allowed only a quantitative cross-sectional ‘snap shot’ that built upon Study One. The general aim of the study was to examine the relationship between benefit finding, emotional experiences, mental health outcomes, and other key variables (e.g. gender, illness variables). Study Two is an exploratory study that will confirm and quantify the benefit finding phenomenon in an adult child cohort. The Study Two research aims and hypotheses were as follows.

*Research Aim 1:* To confirm the presence of benefit finding in adults, whose parents have cancer, and examine the types of benefits that are reported by this cohort.

Specific hypotheses:

1.1. That benefit finding will be present in a sample of adult children of cancer patients.
1.2. That benefits relating to the sick parent and family will be the most frequently reported type of benefit.
1.3. That benefits relating to personal development will be the least frequently reported type of benefit.

The finding from Study One that benefit finding may be related to emotional reactions and/or involvement in caregiving is potentially very important, as it supports the underlying premise of several posttraumatic growth theories, while also providing some insight into the context within which benefit finding develops. However, to further understand the context within which benefits emerge, it was deemed prudent to include several illness-related variables, as previous studies (e.g., Compas et al., 1994; Oktay, 2005) have suggested that illness characteristics may influence adjustment to parental cancer. The prediction of benefit finding is, therefore, one of the key areas of investigation in Study Two, with the following aims and hypotheses to be tested:
Research Aim 2: To examine the role of negative experiential elements (i.e., emotional experiences and caregiver strain) and illness variables (e.g., parental gender, outcome of cancer) in predicting benefit finding in the adult children of cancer patients.

Specific hypotheses:

2.1. That emotional experience (as measured by the emotional experiences subscale of the PCQ) would be predictive of benefit finding.
2.2. That involvement in caregiving (as measured by the caregiver strain subscale of the PCQ and 0-10 rating) would be predictive of benefit finding.
2.3. That the illness variables of a parent’s gender, the outcome of illness, and the time since diagnosis might assist in the prediction of benefit finding.

With the evidence of the combined findings from Study One and the existing literature suggesting that benefit finding was an outcome of parental cancer, it was also decided to examine the role that benefit finding may play in the psychological outcomes among adult children. An examination of the literature of cancer patients and spouses has revealed that there is an inconsistent pattern of findings in relation to benefit finding, depression, anxiety, and well-being. Despite these inconsistent reviews, it was thought that a modest relationship would be found between benefit finding and depression. In the light of the inconsistent empirical results, and the theoretical contention that posttraumatic growth contributes to more negative world views, it was argued that benefit finding would not be predictive of well-being. Furthermore, in the light of the relationship between benefit finding, emotional reaction and involvement in care demonstrated in Study One, it was decided to test the variables of emotional reaction, caregiver strain, and involvement in care in the prediction of psychological outcomes.

Research Aim 3: To examine the role of benefit finding in the prediction of the mental health outcomes of depression, anxiety, stress and well-being arising from parental cancer.
Specific hypotheses:

3.1. That benefit finding, emotional experiences, and caregiving would be predictive of depression.

3.2. That benefit finding would not be predictive of anxiety, stress or well being; however, the variables of emotional experiences and caregiving would be predictive of those psychological outcomes.

3.3. Those individuals reporting high levels of benefit finding would differ from individuals with low levels of benefit finding in terms of depression.

With a view to test the aims and hypotheses outlined above the author commenced planning for Study Two. A crucial element of the study was quantifying the themes that emerged in Study One. An extensive literature review examined and evaluated scales that measured the emotional experience of illness, benefit finding, and caregiving. No single measure was found that assesses all areas and that; overall, there was a lack of psychometrically sound measures which assess the emotional response of adult offspring in relation to parental illness (See Appendix G for a summary of the scales reviewed and the reasons for determining them unsuitable). Consequently, an appropriate scale needed to be developed to gauge the impact of parental illness, and allow for its relationship with other key variables (e.g., benefit finding) to be determined. To address this limitation, the author decided to develop a measure based on the data obtained in Study One. Once this decision was made, it was decided that the measure should not only focus on the emotional aspect of the experience, but try to measure both positive and negative elements (as suggested by Park, 2004). As such, the new measure was developed around the seven themes highlighted by Study One (see Chapter 6, Section 6.2.1 for further details relating to scale development). Arising from this decision, an additional research aim was:

*Research Aim 4:* To develop a reliable measure with a clear component structure which describes the multiple aspects of the parental cancer experience of adult children.
It is important to stress to the reader that the development of a scale was not the intention of the author during the initial conceptualisation of this thesis and, therefore, this thesis should not be viewed as an extensive psychometric study. Rather, the scale was developed to address a perceived need, but the main focus of the study remained the first three research aims. However, the author acknowledges that scale development, without performing analysis on scale structure and reliability, or collecting information to support the scale’s validity, represents poor research practice. Consequently, Study Two also included scales to help develop the new measure’s psychometric properties, and this information is reported in Chapter 7.

6.1.1. Development of the Parental Cancer Questionnaire (PCQ).

As outlined earlier, the PCQ was devised by the present author for use in the current study, due to the lack of a suitable existing scale (see Appendix G for an examination of the scales reviewed for possible use). Development of the PCQ was guided by the process of scale development suggested by Bradburn, Sudman, and Wansink (2004), Dillman (2000), and E. Martin (2006). The PCQ aims to examine both positive (i.e., perceived benefits) and negative aspects (i.e., emotional reaction, grief, demands of caregiving) associated with parental cancer and, therefore, may assist both researchers and practitioners to get a balanced understanding of the issues arising from this experience. The scale was derived from the data collected in the qualitative study, with questions being constructed around the key themes and the language used by participants in describing their experience of parental cancer. An original item pool of 127 items was constructed, representing the themes and sub-themes from the qualitative study. Items were also written with reference to the verbatim responses of participants in Study One to ensure representation of the style of language used by participants. This aimed to imbue face validity, particularly in regard to the language employed in the items. Close reliance on the Study One themes also ensured the content validity of the measure.
The next step involved the use of expert feedback on question content, and consultation in relation to scale instructions and response format. As suggested by Bradburn et al. (2004) the draft scale was then circulated to a small group of adults whose parents have cancer \((n = 6)\) and a psycho-oncologist for pre-testing. This group was asked to provide feedback regarding the face validity of the scale, the item wording and relevance, and to identify redundant items. Based on this feedback, and in review with the pilot study data, the PCQ items were refined and reduced to the 53 item scale that was used in the current study.

The PCQ used in this study was constructed to reflect the main themes and sub-themes derived from Study One, and contains the following subscales: (a) sick parent benefits (6 items, e.g., Communication between my sick parent and I improved); (b) family matters (6 items, e.g., My parent’s cancer has helped me recognise the importance and value of family); (c) altered life priorities (7 items, e.g., My parent’s cancer changed my outlook on life for the better); (d) personal development (6 items, e.g., I feel I have become more resilient as a result of what I went through when my parent was sick); (e) experience intensity (8 items, e.g., My parent’s cancer has been a traumatic experience for me); (f) grief and loss (6 items, e.g., I feel great sadness when I think about my parent’s cancer); and (g) involvement in care (14 items, e.g., I was stressed by my involvement in my parent’s care).

The participants were asked to indicate their level of agreement with each statement with responses made, using a seven-point Likert scale \((1 = \text{“Very strongly disagree”} \text{ to } 7 \text{ “Very strongly agree”})\), with a 0 option representing \text{“not applicable.”} For scoring purposes, items 42 and 47 were reverse scored. The PCQ was subjected to principal components analysis and reliability and validity analyses were performed on the final structure (see Chapter 7 for details).
6.2. Methodology

6.2.1 Participants.

A total of 352 adults participated in the study; however, following data entry and screening, the sample was reduced to 311 participants. Case deletions were made due to participants only completing the demographic section, or violating the inclusion criteria set for the study. Specifically, the inclusion criteria stated that participants must be: (a) Over 18 years of age at the time their parent was diagnosed with cancer; (b) their parent was diagnosed with cancer at least 12 months prior to participation in the study; and (c) that if their parent had passed away, that loss occurred at least six months ago.

Of the 311 participants, 255 (82.5%) were female and 54 (17.5%) were male. The participants were asked to indicate their current age, using age categories (e.g., aged 26-30 years), and the participants’ ages ranged from 18-25 years to over 70 years. The modal age range was 41-45 years ($n = 49$), and the majority of responses were provided by individuals aged between 31 and 50 years ($n = 174, 56\%$). A range of religious affiliations were reported by participants, however, the most common category indicated for religion was “no religious affiliation” ($n = 106, 34.4\%$). Other common religions reported in the sample include: Catholic ($n = 76, 24.7\%$), Anglican ($n = 52, 16.9\%$), Church of England ($n = 19, 6.2\%$), and Uniting ($n = 15, 4.9\%$).

Information pertaining to family composition and a personal diagnosis of cancer were collected. The number of siblings reported by participants ranged from zero to eight ($M = 2.08, SD = 1.40$), with the modal number of siblings being one. As gender is potentially an important variable in the distribution of caregiving within families, questions were asked in relation to the number of brothers and sisters. The number of brothers ranged from 0-7 (mode = 1) and number of sisters ranged from 0-4 (mode = 0). Having received a personal diagnosis of cancer represents a potential confounding variable in the sample, and therefore participants were asked

11 There are occasions where the $N$ for additions of groups (e.g., 255 females and 54 males above) does not equal the total $N$ of the study (i.e., 311). This represents non-response to that demographic item by a small number of participants.
whether they had ever been diagnosed with cancer. From the sample, 53 (17.0%) had been diagnosed with cancer at some stage in their life, while the remaining 255 (83.0%) had not been diagnosed with cancer. Analyses were conducted to examine whether there were differences on key variables based on individual cancer diagnosis, however no significant differences were found, and therefore no additional separate analyses based on this variable were performed.

In terms of the gender of the parent with cancer, 197 (63.3%) participants reported on the experience of having a mother with cancer, 109 (35%) participants had a father with cancer, three (1%) participants had a step-father with cancer, and two participants (0.6%) had a step-mother with cancer. The age of participants when their parent was diagnosed with cancer ranged from 18 – 58 years, with the mean age being 33.6 years \((SD = 9.63)\). Participants were also asked how long it had been since their parent recovered or passed away (with an option for treatment still ongoing) to gauge the passage of time since their parent was ill. The period since recovery/passing away ranged from three months to 50 years, with a mean of 8.54 years \((SD = 9.68)\). Fifty-one participants indicated that treatment was ongoing.

The most common forms of parental cancer included in the sample were: breast \((n = 82, 26.5\%)\), bowel \((n = 53, 17.1\%)\), prostate \((n = 32, 10.3\%)\), ovarian \((n = 31, 10.0\%)\), lung \((n = 22, 7.1\%)\), multiple myeloma \((n = 15, 4.8\%)\), pancreatic \((n = 14, 4.5\%)\), and lymphoma \((n = 13, 4.2\%)\). In relation to the outcome of their parent’s cancer, 165 (53.1%) participants reported that their parent was deceased, 89 (28.6%) reported that their parent had been treated successfully (i.e., was currently cancer free), 30 (9.6%) reported their parent had been treated, but that the cancer had recurred or spread, 25 (8.0%) reported their parent was currently undergoing treatment, and two (0.6%) cases indicated an “other” outcome. Participants were also asked how long their parent had been ill with cancer, to which they responded using the following categories: less than six months \((n = 48, 15.4\%)\), six – 12 months \((n = 77, 24.8\%)\), 1-2 years \((n = 53, 17.0\%)\), 2-3 years \((n = 40, 12.9\%)\), 3-4 years \((n = 15, 4.8\%)\), 4-5 years \((n =
18, 5.8%), and 5 years plus (n = 60, 19.3%). To gain some insight into the state of the parent’s health prior to diagnosis, participants were also asked to rate their parent’s pre-cancer health. Responses were made using the following categories: excellent (n = 95, 30.5%), very good (n = 103, 33.1%), good (n = 71, 22.8%), fair (n = 37, 11.9%), and poor (n = 5, 1.6%). This question was included to determine the degree to which a diagnosis of cancer would represent a change in parent’s health status, and therefore may provide some gauge as to the novelty and potential impact of diagnosis (i.e., was this diagnosis sudden and unprepared for, and therefore a potential trauma, or was it another health issue in an individual already facing several health issues). Analyses were conducted to examine whether there were differences on key variables based on parental pre-cancer health status, however, no significant differences were found, and therefore no additional separate analyses based on this variable were performed.

6.2.2 Instruments.

All participants completed the PCQ (outlined earlier), Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996), Reaction to the Diagnosis of Cancer Questionnaire (Frank-Stromborg, 1989), Grief Diagnostic Instrument (Clark, Marley, Hillier, Leahy, & Pratt, 2005-2006), Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 1995), and the Warwick-Edinburgh Mental Well-being Scale (Tennant et al., 2007). Participants were also asked about their involvement in caring for their parent and, if they were a caregiver, they were required to complete the following additional items: level of involvement in care self-reported on a scale of 0-10, the Carer’s Assessment of Difficulties Index and the Carer’s Assessment of Satisfactions Index (Nolan, Grant, & Keady, 1998). If participants were not involved in their parent’s care, they were asked to indicate all the reasons that prevented them from being involved from a range of options, including: choice, geographical distance, workload, own family, other family members already caring for parent, being asked not to by the parent, lack of care-related skills, fear of cancer, already caring for someone else, and other (please specify). All participants were invited to provide qualitative comments about their experience of parental cancer at the end of the survey. A copy of the questionnaire is included in Appendix H.
6.2.2.1 Posttraumatic Growth Inventory (PTGI).

The PTGI was developed by Tedeschi and Calhoun (1996) to assess potential positive outcomes that may arise for individuals, who have experienced traumatic event/s. The 21 item scale contains five subscales: (a) relating to others (7 items); (b) new possibilities (5 items); (c) personal strength (4 items); (d) spiritual change (2 items); and (e) appreciation for life (3 items). Example items for each subscale include: “I put more effort into my relationships” (relating to others), “I have developed new interests” (new possibilities), “I have a greater feeling of self-reliance” (personal strength), “I have a better understanding of spiritual matters” (spiritual change), and “I can better appreciate each day” (appreciation of life). Participants were asked to read each statement, and then respond using a six-point scale where 0 = “I did not experience this change as a result of my parent’s cancer” and 5 = “I experienced this change to a very great degree as a result of my parent’s cancer.” Sub-scale scores were calculated by adding items on that sub-scale, and a total growth score was obtained through summing all 21 items. The PTGI was used in Study Two primarily as a means to establish that validity of the benefit-related subscales on the PCQ. The inclusion of the PTGI for this purpose was based on the grounds that it is one of the two most widely used measures in studies of posttraumatic growth and benefit finding (Helgeson, Reynolds & Tomich, 2006), and that it is a well-validated and standardised measure (Zoellner & Maercker, 2006).

The PTGI was developed through a review of trauma-related growth literature, and reflects positive changes that are frequently mentioned as outcomes arising from negative life events. Tedeschi and Calhoun (1996) generated and tested an item pool of 34 items with a sample of 604 university undergraduates, who had experienced a range of negative events, including bereavement, injury-producing accidents, parental divorce, relationship breakdown and criminal victimisation. Based on principal components analysis, the item pool was reduced to 21 items with five subscales. Overall, the PTGI reports excellent internal consistency with $\alpha = .90$. In addition, the subscales report solid reliability as follows: relating to others $\alpha = .85$, new possibilities $\alpha = .84$, personal strength $\alpha = .72$, spiritual
change $\alpha = .85$, and appreciation for life $\alpha = .67$ (Tedeschi & Calhoun, 1996). In the present study, the reliability coefficients for the total PTGI and the subscales were as follows: PTGI total $\alpha = .95$, relating to others $\alpha = .90$, new possibilities $\alpha = .88$, personal strength $\alpha = .87$, spiritual change $\alpha = .82$, and appreciation for life $\alpha = .85$.

The PTGI has demonstrated numerous types of validity (Tedeschi & Calhoun, 1996). Concurrent and discriminant validity were examined using scales of social desirability, personality, and religiosity. It was predicted that the PTGI would be unrelated to social desirability, positively correlated with optimism, extraversion, openness, and religiosity, and negatively correlated with neuroticism, with all expected relationships being confirmed (Tedeschi & Calhoun, 1996). The construct validity of the PTGI was demonstrated in a sample of 194 college students with participants, who reported the experience of a traumatic event, reporting higher levels of benefits compared to participants, who had not been exposed to a traumatic stressor. This pattern was reported for the total PTGI score and all sub-scales, except spiritual change (Tedeschi & Calhoun, 1996).

6.2.2.2 Carer’s Assessment of Difficulties Scale (CADI) and Carer’s Assessment of Satisfactions Scale (CASI).

The CADI and CASI were developed by Nolan, Grant, and Keady (1998) as part of a test battery to assess care-related strains, satisfactions and coping approaches. Specifically, the developers argued that much was known about the stresses and strains faced by carers, but little was known about the satisfactions derived from caring, and how people cope with their care-related stressors (Nolan et al., 1998). For this study, the coping measure was not used. The scales were developed, based on research and clinical work by Nolan et al. (1998) and use the transactional model of stress as their theoretical basis. The inclusion of the CASI represents the position that, in a caregiving context, both the stressors and rewards must be examined concurrently. Item content was largely taken from consultations with carers, and from a review of caregiving literature (Nolan et al., 1998). The factor structure of the CADI was derived from research conducted by
Nolan and Grant (1992). The measures were employed in the present study to develop the validity of the benefit and care-related subscales of the PCQ.

The CADI is a 30 item questionnaire, examining common difficulties that carers might face across multiple life domains. There are seven subscales measuring: (a) carer-dependant relationship (7 items, e.g., I no longer have a meaningful relationship with the person I care for); (b) reactions to caregiving (7 items, e.g., My emotional well-being suffers); (c) physical demands of caregiving (6 items, e.g., It is physically tiring); (d) restricted social life (3 items, e.g., I can’t have a break or take a holiday); (e) poor family support (2 items, e.g., Relatives don’t keep in touch as often as I’d like); (f) poor professional support (2 items, e.g., I don’t get enough help from health and social services); and (g) financial consequences (2 items, e.g., My standard of living has fallen). Participants were asked to read each statement and then respond, using a four-point scale where 0 = “This does not apply to me,” 1 = “Not stressful,” 2 = “Stressful,” and 3 = “Very stressful.” Sub-scale scores were calculated by adding all items on that sub-scale, and a total difficulty score was obtained through summing all 30 items. Nolan et al. (1998) report the overall reliability of the CADI to be .92, with sub-scale reliabilities ranging from .71-.84. In the current study, the following reliability co-efficients were obtained for the CADI and its subscales: CADI total $\alpha = .92$, carer-dependant relationship $\alpha = .80$, reactions to caregiving $\alpha = .81$, physical demands of caregiving $\alpha = .81$, restricted social life $\alpha = .83$, poor family support $\alpha = .77$, poor professional support $\alpha = .69$, and financial consequences $\alpha = .56$. It is acknowledged by the author that the reliability of the professional support and financial consequences subscales are lower than required for research purposes, however, no analyses were conducted using these individual subscales.

The CASI is a 30 item questionnaire that the developers argue should not be divided into sub-scales, but rather the individual pattern of responding should be examined to construct a profile of satisfactions relating to the caring experience (Nolan et al., 1998). While this may be appropriate in a clinical setting, for use in the current research the CASI has been used as a single scale, with a total satisfactions score created by adding
all items. Example items from the CASI include “Caring enables me to fulfil my sense of duty” and “It’s nice to feel appreciated by those family and friends I value.” Participants were asked to read each statement and then respond using a four-point where 0 = “This does not apply to me,” 1 = “No real satisfaction,” 2 = “Quite a lot of satisfaction,” and 3 = “A great deal of satisfaction.” Nolan et al. (1998) report the overall reliability of the CASI to be .91, and in the present study Cronbach’s alpha for the CASI was .93.

6.2.2.3 Reaction to Diagnosis of Cancer Questionnaire (RDCQ).

The RDCQ was developed by Frank-Stromborg (1989) to assess the initial reaction of patients to a diagnosis of cancer, specifically to investigate both emotional distress, but also more confronting reactions. The 28 item scale contains two sub-scales: distress and confrontation. The distress subscale (19 items) represents the negative emotional reactions to diagnosis, which the developer argues indicates a less adaptive reaction to the cancer diagnosis (Frank-Stromborg, 1989). Examples of distress items include “I was scared” and “I felt helpless.” The confrontation subscale (9 items) represents a more determined reaction that indicates a desire to confront or ‘fight’ the disease. Examples of confrontation items include “I began to hope” and “I decided cancer wouldn’t get the best of me.” For use in the current study, the wording of the instructions and some items were changed to make them relevant to the cohort (e.g., the item “I knew I was going to die” was changed to “I knew my parent was going to die”). The scale instructions stated “What do you remember feeling after you heard the diagnosis of your parent’s cancer?” Participants indicated the degree to which they felt a particular reaction, using a five-point Likert scale where 1 = “No I did not feel that way at all” and 5 = “Yes, I felt that way extremely.” Distress items were reversed scored, so that higher scores indicated a higher level of confronting response and lower scores indicated stronger distress reactions. Subscale totals were then obtained by adding the items on that subscale. The RDCQ was used in Study Two to establish the validity of the subscale of the PCQ that pertained to negative emotional reactions.
Items on the RDCQ were developed by asking 340 cancer patients to recall their feelings at the time of diagnosis, with their answers being subjected to content analysis. Based on content analysis, literature reviews, additional data obtained through patient interviews and categorisation by oncology nursing staff, the items were classified as belonging to either the distress or confronting subscales. Test-retest reliability over a three week period is reported as $r = 0.86$. The psychometric properties and confirmation of the factor structure of the RDCQ were established through a second study, involving 441 ambulatory cancer patients. This study utilised a 36 item version of the RDCQ, which was reduced to 28 items through examination of the item-total correlation coefficients and inter-item correlations. Initial principal components analysis suggested the presence of six factors; however, second-order factor analysis confirmed the presence of only two factors, namely distress and confrontation. The reliability of the total RDCQ was reported as $\alpha = .90$, with the subscale reliability coefficients of $\alpha = .91$ for distress items and $\alpha = .82$ for confrontation items (Frank-Stromborg, 1989). As the RDCQ was adjusted for use with a different target cohort, in this study it was important to assess the reliability of this scale. In the present study, the reliability for the overall scale, distress and confrontation subscales was found to be $\alpha = .85$, $\alpha = .92$, and $\alpha = .85$ respectively.

6.2.2.4 Grief Diagnostic Instrument (GDI).

The GDI was developed by Clark et al. (2005-06), and purports to be a general measure of grief arising from any loss (i.e., it is not specific to bereavement, although it could be used in that context). This scale was developed for use primarily in the General Practice environment to assist doctors in the identification of emotional problems arising from loss, which may be under-recognised in the community. The GDI was deemed particularly appropriate for use in the current study, as its broad definitions of grief and loss make it a suitable tool for assessing grief from: (a) past, present and impending losses; (b) death and non-death related losses that may be present at various stages of the parental cancer experience; and (c) losses occurring directly to the individual or in sympathy with the grief from others’ losses (e.g., if their parent had to retire from work as a result of their
cancer, they may grieve the loss of their parent’s work-related identity in sympathy with their parent). The GDI was used in the present study to develop the validity of the grief and loss subscale of the PCQ.

The GDI contains three sections: (a) demographics; (b) loss categories in which individuals indicate, using yes or no, whether they have experienced distress relating to a form of loss (e.g., job loss, pregnancy, pet, separation, loss of a loved one) in the last two weeks; and (c) a grief scale aimed to measure the state of grief arising from the losses identified in Section B of the scale. For the purposes of this study, participants completed only the items on Section C (referred to as GDI-C), and were asked to answer the questions in relation to their experience of having a parent with cancer. Example items from the GDI-C, modified for inclusion in this study, include “Have you experienced images of the events surrounding your parent’s cancer?” and “Have thoughts or reminders of the loss or loss situation caused you to feel numb?” Participants indicated their degree of distress using a four-point Likert scale, where 0 = “no distress/never,” 1 = “slightly distressful/a little bit of the time,” 2 = “quite distressful/quite a bit of the time,” and 3 = “exceedingly distressful/continuously/a lot of the time.” Total grief scores were obtained by summing the scores of all items.

The GDI was developed by Clark et al. (2005-06) over a four phase process of design, pilot, trial and evaluation. The items in Section C were taken from other measures of grief and related mental health conditions, and modified as needed to become relevant to past/present/future losses and death/non-death related losses. This resulted in a 53 item scale that was tested in the pilot phase. The pilot study identified that Section C was overly long and repetitious; it was therefore revised and reduced to 27 items. Further items were deleted during the trial and evaluation phases, resulting in the final 16 item version of this section. Items were deleted based on the grounds of poor face validity, discriminatory validity, internal consistency, and measurement principles determined by the authors as appropriate for assessing psychological phenomena (Clark et al., 2005-06). In addition, a modified Q-sort technique was used to eliminate items with duplicated meaning. The reliability of the final 16 item GDI-C was found to be $\alpha = .93,$
suggesting high internal consistency of the measure (Clark et al., 2005-06). In the present study, the reliability of the GDI-C was $\alpha = .95$.

6.2.2.5 Depression, Anxiety and Stress Scale – Short Version (DASS).

The negative emotional states of depression, anxiety and stress were assessed using the short version of the DASS (Lovibond & Lovibond, 1995). The three subscales each contain seven items, which represent characteristic symptoms associated with each emotional state (e.g., dysphoria, autonomic arousal and agitation). Depression items include “I couldn’t seem to experience any positive feeling at all,” and “I felt I wasn’t worth much as a person.” Anxiety items include “I felt I was close to panic,” and “I felt scared without any good reason.” Stress items include “I found it hard to wind down,” and “I tended to over-react to situations.” Participants signify how indicative each statement is of their emotional state over the past two weeks, using the response options of: 0 = “Did not apply to me at all,” 1 = “Applied to me to some degree, or some of the time,” 2 = “Applied to me a considerable degree, or a good part of the time,” or 3 “Applied to me very much, or most of the time.” The scores on items that constitute each subscale were added together, and multiplied by two to provide a score on each dimension. This score was then used to determine the level of negative affect for the individual on each subscale, ranging from normal to extremely severe. The DASS was used in Study Two as a measure of negative psychological outcomes, with the view of testing whether benefit finding is predictive of such outcomes.

Lovibond and Lovibond (1995) report that the DASS possesses solid psychometric properties. The instrument was designed in Australia, and the full version has been normed on a variety of adult samples including university students, depressive outpatients, myocardial infarction patients and insomniacs ($N = 2914$). The short version of the DASS has been studied, using a normative sample of 717 psychology students. Each subscale of the DASS short form has reliability coefficients of $\alpha = .73$ and above (Lovibond & Lovibond, 1995), with the reliability of the subscales in the current study being: Depression $\alpha = .91$, Anxiety $\alpha = .87$ and Stress $\alpha =$
.92. The original DASS instrument, from which the shortened 21 item DASS is derived, has demonstrated convergent validity with the Beck Depression Inventory \( (r = .74) \) and the Beck Anxiety Inventory \( (r = .81; \) Lovibond & Lovibond, 1995).

6.2.2.6 Warwick-Edinburgh Mental Well-being Scale (WEMWBS).

The WEMWBS was developed by researchers at the Warwick and Edinburgh Universities,\(^{12}\) and aims to measure mental well-being, specifically both the hedonic aspects of well-being (i.e., subjective experience of positive affect and life satisfaction) and eudaimonic aspects (i.e., psychological functioning, self-realisation and positive relationships with others; Stewart-Brown & Janmohamed, 2008). The WEMWBS consists of 14 items, to which individuals indicate the extent to which they have experienced such thoughts and feelings over the past two weeks. Example items from the WEMWBS include “I’ve been feeling loved,” and “I’ve had energy to spare.” Participants respond using a five-point Likert scale, with the following response options: 1 = “None of the time,” 2 = “Rarely,” 3 = “Some of the time,” 4 = “Often,” and 5 = “All of the time.” Total well-being scores were obtained by adding all items, with higher scores indicating higher levels of well-being. The WEMWBS was used in the present study as a measure of a positive psychological outcome, with the aim of determining whether benefit finding was related to, and predictive of, well-being.

Considerable work has gone into the development of the WEMWBS, resulting in a psychometrically sound instrument. The WEMWBS emerged from an examination of existing well-being measures, with a specific focus on the Affectometer 2 (Kammann & Flett, 1983). Focus groups, consisting of community members and mental health patients, were conducted to determine flaws with the Affectometer 2, such as length and ambiguous items. Following the focus groups, expert panel reviews were conducted, and it was determined that a new scale, containing only positively worded

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\(^{12}\) The Warwick-Edinburgh Mental Well-being Scale was funded by the Scottish Executive National Programme for improving mental health and well-being, commissioned by NHS Health Scotland, developed by the University of Warwick and the University of Edinburgh, and is jointly owned by NHS Health Scotland, the University of Warwick and the University of Edinburgh.
items, was required to assess positive mental health (Tennant et al., 2007). Extensive testing in both community and students samples was conducted to ascertain the psychometric properties of the WEMWBS. Factor analysis confirmed the presence of a single factor, and a reliability analysis found strong internal consistencies, with $\alpha = .89$ in student samples and $\alpha = .91$ in community samples (Tennant et al., 2007). The reliability of the WEMWBS in the current study was $\alpha = .95$. Test-retest reliability is also high, reported at .83 (Tennant et al., 2007). The construct validity of the measure has been demonstrated through correlations with other measures of mental health, specifically the WHO-Five Well-being Index ($r = .77$), Positive and Negative Affect Scale ($r = .73$ positive affect subscale, $r = -.55$ negative affect scale), Satisfaction with Life Scale ($r = .72$) and the Scale of Psychological Well-being ($r = .73$; Stewart-Brown & Janmohamed, 2008).

6.2.2.7 Involvement in Caregiving.

In addition to the measures outlined above, participants were asked to indicate their level of involvement in care on a scale of 0-10, with 0 indicating no involvement and 10 indicating they were their parent’s full time carer. This single item measure was used to gauge participants’ perception of their involvement in caregiving, as involvement in care had been identified in Study One as a variable that may potentially influence the level of benefits reported. Seventy-six (24%) participants indicated they were not involved in caring for their parent, and therefore did not need to complete the CADI or CASI.

6.2.3 Procedure.

Ethics approval for the study was obtained through application to Charles Sturt University Ethics in Human Research Committee (see Appendix I). Prior to the commencement of the study, an on-line search was done to find contact details for cancer-related organisations and support groups. From this search, a database of 660 organisations and support groups were identified across all states and territories of Australia. Letters were mailed to all organisations; informing them of the research and inviting them to pass on information about the study (see Appendix J). Options for passing on information included the circulation of a promotional
flyer or project information sheet to members, promotion of the research in their newsletters and/or on their website, or having the author attend a meeting to discuss the study (Sydney metropolitan groups only). From the 660 letters sent out, responses were received from 239 organisations, with 158 organisations agreeing to help recruit participants for the study (see Appendix K for a list of supporting organisations). While this represents a low response rate of 24% of the total letters sent out. However, in terms of the number of responses received, 67% of organisations indicated a willingness to assist in participant recruitment. Most organisations assisted by circulating information sheets/promotional flyers (77%), with a smaller percentage placing articles in their newsletters (28%), links on websites (11%) or requesting the author attend a meeting (2%). In addition, six organisations directly distributed surveys to their members (4%). Overall, 93 (30%) participants were recruited through information circulated by support groups/organisations, 50 (16%) through website links, and 25 (8%) through direct contact with the author.

In addition to recruiting via support organisations, the study was also promoted through the use of a Charles Sturt University electronic daily news message and student/staff electronic forums. This strategy was designed to widen the variability of the sample, and ensure that individuals, who may not be accessing support services, were also included in the sample. On four occasions between the months of February and May 2010, electronic messages were circulated inviting people to participate in the study (see Appendix L). Overall, 47 participants (15%) were recruited via this strategy. The remaining 74 (24%) participants indicating they found out about the study through ‘other’ means, the most common of which was having information about the study provided to them by their parent.

Participants had the option of completing the survey on-line through the survey monkey website, or contacting the author for a pen-and-paper version to be mailed to them. The majority of participants completed the survey on-line ($n = 245$) with the remaining participants submitting their survey via mail ($n = 66$). Analysis revealed that the on-line submitters were generally younger than postal submissions, and this seems logical as many
older people may feel that they do not have the necessary skills or access to technology to submit on-line. It was estimated that it would take participants approximately 60 minutes to complete the survey. At the conclusion of the data collection phase all collected data was combined into PASW 18 for analyses.

In summary, this chapter has detailed the method utilised in Study Two, outlining characteristics of the sample, reviewing the measures in the composite questionnaire, and explaining the procedure undertaken for recruitment and participation. The following two chapters contain detailed results of Study Two. Chapter Seven outlines the principal components analysis of the PCQ, and Chapter Eight reports the tests to examine key research aims and hypotheses.
Chapter 7: Study Two Principal Components Analysis of the Parental Cancer Questionnaire (PCQ)

The PCQ was developed in order to study key variables relating to parental cancer not measured in existing scales. The content of the PCQ was derived directly from the semi-structured interviews in Study One. The scale was then subjected to review by adults, whose parents had cancer, and a psycho-oncologist, before being reduced to the 53 items employed in Study Two. This chapter represents the next step in the scale’s development, namely a quantitative examination of the scale’s structure through principal components analysis. The chapter outlines the process that was undertaken to determine the final component structure of the scale, and presents data in relation to the measure’s reliability and validity.

7.1 Determining the Component Structure of the PCQ

The first stage of data analysis was to perform principal components analysis on the PCQ to determine its component structure. Principal components analysis is a multivariate technique, which allows for the identification of underlying dimensions, or components, from a large set of variables (Harlow, 2005), and is therefore suited to the investigation of scale structure.

The assumptions of principal components analysis were considered during the planning and data screening stages of the study. Specifically, the data should be independent, and the minimum sample size required for analysis was determined to be \( n = 265 \) (minimum of 5 participants per variable; Allen & Bennett, 2010), which has been exceeded with the current sample size \( (n = 311) \). Outliers were detected in some items, and a consideration of transformation options was undertaken. There is debate regarding the criterion to be set for such alterations (e.g., three or four standard deviations, highest or lowest score +1 [Cousineau & Chartier, 2010; Tabachnick & Fidell, 2007; Wuensch, 2008]). However, in the current study, outliers were transformed to a value 3 standard deviations above or below the mean (Field, 2009), thus allowing the relative ranking of scores to be maintained, whilst reducing skew and error variance (Osborne
& Overbay, 2004). In terms of the assumption of normality, all items have significant Shapiro-Wilks tests, indicating that responses were not normally distributed. As the Shapiro-Wilks test is very sensitive to minor departures from normality, a visual examination of normality plots (i.e., histograms and stem and leaf diagrams) was conducted. This visual examination suggested that most items are reasonably normally distributed, with most deviations representing skewed items, rather than more significant variations to normality (e.g., bimodal distributions). In the light of this visual examination, and the consideration that principal components analysis is relatively robust against violations to normality (Allen & Bennett, 2010), no transformations to the data were performed. The assumptions of linearity and multicollinearity were not violated by the data. Additional tests assessing the data’s suitability for component analysis were conducted and found to be adequate. Specifically, the Kaiser-Meyer-Olkin (KMO) Measure of Sampling Adequacy was .86, which exceeds the .60 standard required for factor analysis (Allen & Bennett, 2010). Bartlett’s Test of Sphericity was also conducted and found to be significant ($p < .001$), suggesting that the data is suitable for principal components analysis.

Exploratory principal components analysis was conducted to determine the sub-structure of the PCQ. Tabachnick and Fidell (2007) suggest that exploratory principal components analysis aims to describe and summarise data, by grouping together correlated variables, and is inherently suitable for the early stages of research, as was the case in the current study. As it was expected that there would be a relationship between the components (as suggested by the data in Study One), oblique rotation was selected as the extraction technique (Kline, 1994; Tabachnick & Fidell, 2007). As the items of the PCQ were derived from the seven themes extracted from the pilot study data, the analysis was restricted to generate a seven component structure. Although it was expected that seven sub-scales would be present, principal components analysis was still considered exploratory, rather than confirmatory, as results were to provide the initial assessment of the construct validity of the PCQ.

\[13\] Note that the statistics reported here relate to the final principal components analysis, but are presented here to demonstrate the steps taken to ensure that the data was suitable for this analysis.
The following four rules of thumb were used as a guide in determining the components: (a) percentage of variance accounted for by the component (Harlow, 2005); (b) eigenvalues greater than 1 (Rummel, 1970; Stevens, 2002); (c) scree plots (Harlow, 2005; Rummel, 1970); and (d) a qualitative assessment of the interpretability of the components, or meaningfulness (Harlow, 2005; Rummel, 1970). It is noted, however, that while these rules of thumb were used as a guide, they were not applied as rigid rules and, at times, the qualitative interpretability of the component structure was the primary source for making decisions during analysis. The emphasis on qualitative interpretability was due to the aim being to produce a component structure that was clear, reliable, and consistent with both the data from Study One and the cancer-related growth literature.

A priori analyses criteria were established in order to guide decision making regarding the order of item deletion and item retention. Specifically, the order in which items were to be deleted was: (a) if the highest component loading for that item was on a component that did not fit conceptually in light of the data obtained in Study One (e.g., if an altered priority item loaded strongest on the component representing sick parent benefits); (b) the highest loading was conceptually consistent, but the item also loaded above .4 on a component that was not conceptually related (e.g., if benefit items cross-loaded on emotional experience items and vice versa); and finally (c) if the item cross-loaded at above .4 on any component. Cross-loading items were deleted, as the aim was to produce a scale with distinct components that represent unique aspects of the parental cancer experience. Items would be retained on a component, if they loaded at or above .40 on that component only. Using these criteria as a guide, an exhaustive series of analyses were conducted to establish a clear number of components that best described the structure of the PCQ. As mentioned above, initially a seven component structure was sought. However, after items were deleted for conceptual and cross-loading reasons, the seven component structure became unviable. Specifically, six components were present: (a) sick parent benefits; (b) family-related benefits; (c) altered life priorities; (d) personal development; (e) emotional experiences; and (f)
caregiver strain. There were no items that had their strongest loadings on Component 7. Additionally, the two items that did load above .4 on Component 7 were conceptually unrelated, and therefore could not be used to create a conceptually coherent component.

In the light of the inability to create a seven component scale structure, analyses were then conducted based on a six component solution. Again, using the criteria set out above, it was found that a six component structure was not viable, with again one component having no items loading on it the strongest. This pattern of analysis was repeated again with both five component and four component solutions. However, after a series of analyses, both of these component structures collapsed, with one component failing to load any items at their strongest level in each version. While a component structure representing the multiple benefit themes from Study One was proving unviable, a trend emerged from the analyses indicating that the negative items (i.e., those with negative content representing the non-benefit related experiential aspects of having a parent with cancer) were consistently emerging as two components, one representing the emotional experiences of parental cancer, and one representing caregiver strain. Based on this trend, a three component solution was thought most viable, consisting of a component representing a combination of benefits and the two experience components outlined above.

A three component analysis was then conducted, which led to a clear scale structure. The eigenvalues for the components were 8.82, 4.82 and 3.04, with the next eigenvalue being 1.80. The scree plot also indicated the presence of three strong components, with a possible fourth component being present (i.e., there is the presence of a fourth component before the curve levels off and the incremental difference between the components is about even; Rummel, 1970). Whilst it may be argued that eigenvalues over 1 may constitute viable components, the significant drop off between component 3 and 4, the qualitative interpretability of the components, and the previous analyses all suggest a three component solution as the best structure for the PCQ. Additionally, if the rule of eigenvalues greater than 1
were the defining criteria for scale structure, then the data suggests the PCQ has six components. Previous analyses indicated this as untenable.

Table 7.1 illustrates the three components found in the PCQ, namely parental cancer benefits (PCB), emotional experiences (EE), and caregiver strain (CS). Total variance explained was 51%, which meets the minimum assessment of viability proposed by Harlow (2005), who argues that a reasonable component structure will explain at least 50% of the variance amongst scale items.
Table 7.1
Component Loadings for Exploratory Principal Components Analysis with Direct Oblimin Rotation of Parental Cancer Questionnaire

<table>
<thead>
<tr>
<th>Item</th>
<th>PCQ-B</th>
<th>PCQ-E</th>
<th>PCQ-C</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I became closer to my sick parent during his/her cancer</td>
<td>-0.67</td>
<td>0.28</td>
<td>0.15</td>
</tr>
<tr>
<td>2. I have gotten to know my sick parent on a more meaningful level</td>
<td>-0.69</td>
<td>0.22</td>
<td>0.13</td>
</tr>
<tr>
<td>3. Communication between my sick parent and me improved</td>
<td>-0.77</td>
<td>0.07</td>
<td>0.11</td>
</tr>
<tr>
<td>4. My sick parent and I enjoyed a broader range of activities together after he/she was diagnosed</td>
<td>-0.66</td>
<td>-0.02</td>
<td>-0.05</td>
</tr>
<tr>
<td>5. I developed a greater respect for my sick parent as a result of his/her cancer experience</td>
<td>-0.60</td>
<td>0.23</td>
<td>-0.05</td>
</tr>
<tr>
<td>6. My parent’s cancer gave me a chance to resolve past problem/s with my sick parent</td>
<td>-0.60</td>
<td>0.15</td>
<td>0.16</td>
</tr>
<tr>
<td>7. My relationship with my healthy parent improved as a result of my parent’s cancer</td>
<td>-0.59</td>
<td>0.09</td>
<td>0.00</td>
</tr>
<tr>
<td>8. My relationship with at least one of my siblings improved as a result of my parent’s cancer</td>
<td>-0.66</td>
<td>0.13</td>
<td>-0.06</td>
</tr>
<tr>
<td>9. My relationship with other family members (e.g., spouse, own children, uncle, grandparents) improved as a result of my parent’s cancer</td>
<td>-0.72</td>
<td>0.12</td>
<td>0.09</td>
</tr>
<tr>
<td>10. I have a greater sense of connection with my family since my parent was diagnosed with cancer</td>
<td>-0.78</td>
<td>0.16</td>
<td>0.09</td>
</tr>
<tr>
<td>12. Since my parent was diagnosed with cancer I make an effort to spend more time with family</td>
<td>-0.66</td>
<td>0.33</td>
<td>0.24</td>
</tr>
<tr>
<td>15. My parent’s cancer changed my outlook on life for the better</td>
<td>-0.74</td>
<td>0.26</td>
<td>0.20</td>
</tr>
<tr>
<td>16. I have been more willing to try new things since my parent was diagnosed with cancer</td>
<td>-0.65</td>
<td>0.27</td>
<td>0.37</td>
</tr>
<tr>
<td>17. I have achieved a better balance between work/study and home since my parent has had cancer</td>
<td>-0.56</td>
<td>0.20</td>
<td>0.30</td>
</tr>
<tr>
<td>21. I have developed an enhanced sense of spirituality as a result of my parent’s cancer</td>
<td>-0.54</td>
<td>0.28</td>
<td>0.25</td>
</tr>
<tr>
<td>26. My parent’s cancer has been a traumatic experience for me</td>
<td>-0.23</td>
<td><strong>0.76</strong></td>
<td>0.33</td>
</tr>
<tr>
<td>29. I am/was angry that my parent developed cancer</td>
<td>-0.13</td>
<td><strong>0.68</strong></td>
<td>0.25</td>
</tr>
<tr>
<td>Item</td>
<td>PCQ-B</td>
<td>PCQ-E</td>
<td>PCQ-C</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-------</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td>30. I feel/felt helpless when my parent is/was sick</td>
<td>-0.15</td>
<td>0.65</td>
<td>0.24</td>
</tr>
<tr>
<td>31. I would describe my parent’s cancer as the most emotionally</td>
<td>-0.24</td>
<td>0.80</td>
<td>0.24</td>
</tr>
<tr>
<td>difficult thing I have had to go through</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. I was devastated by my parent’s cancer</td>
<td>-0.23</td>
<td>0.83</td>
<td>0.24</td>
</tr>
<tr>
<td>33. I was shocked when my parent was diagnosed with cancer</td>
<td>-0.29</td>
<td>0.64</td>
<td>0.05</td>
</tr>
<tr>
<td>34. I have been unable to accept why my parent got cancer</td>
<td>-0.17</td>
<td>0.64</td>
<td>0.15</td>
</tr>
<tr>
<td>35. My parent’s cancer made me doubt my beliefs (e.g., religion,</td>
<td>-0.16</td>
<td>0.57</td>
<td>0.13</td>
</tr>
<tr>
<td>faith, views on health and medicine, karma)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. I feel haunted by memories of my parent’s suffering</td>
<td>-0.17</td>
<td>0.70</td>
<td>0.32</td>
</tr>
<tr>
<td>37. I feel that I have missed out on important times with my parent</td>
<td>-0.09</td>
<td>0.72</td>
<td>0.33</td>
</tr>
<tr>
<td>as a result of his/her cancer.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>39. I feel great sadness when I think about my parent’s cancer</td>
<td>-0.10</td>
<td>0.74</td>
<td>0.30</td>
</tr>
<tr>
<td>44. I had to change my plans (e.g., vacations, work activities,</td>
<td>-0.07</td>
<td>0.34</td>
<td>0.65</td>
</tr>
<tr>
<td>study) as a result of my parent’s cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>46. At times I resented the disruption that my parent’s cancer</td>
<td>-0.25</td>
<td>0.11</td>
<td>0.76</td>
</tr>
<tr>
<td>brought to my life</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>48. I feel/felt troubled by a great sense of responsibility for my</td>
<td>-0.15</td>
<td>0.34</td>
<td>0.65</td>
</tr>
<tr>
<td>parent during his/her illness.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50. I felt angry that my life was changed because of my parent’s</td>
<td>-0.21</td>
<td>0.24</td>
<td>0.73</td>
</tr>
<tr>
<td>cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>51. I feel/felt there was nobody to assist or support me in caring</td>
<td>-0.08</td>
<td>0.24</td>
<td>0.79</td>
</tr>
<tr>
<td>for my parent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>52. My parent’s cancer made it difficult for me to do the things I</td>
<td>-0.09</td>
<td>0.29</td>
<td>0.85</td>
</tr>
<tr>
<td>wanted to do</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>53. I found it hard to juggle my obligations during my parent’s</td>
<td>-0.08</td>
<td>0.31</td>
<td>0.83</td>
</tr>
<tr>
<td>illness (e.g., work, caregiving, family, leisure)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Variance explained</strong></td>
<td><strong>26.7</strong></td>
<td><strong>14.6</strong></td>
<td><strong>9.2</strong></td>
</tr>
</tbody>
</table>

PCQ-B = Parental Cancer Questionnaire – Benefits subscale, PCQ-E = Parental Cancer Questionnaire - Emotional Experience subscale, PCQ-C = Parental Cancer Questionnaire - Caregiver Strain subscale
7.1.1. Principal components analysis on benefit items.

The reduction of the PCQ from its originally conceptualised seven components to three components was seen as a point of concern, because extracting too few components can distort the component structure (Rummel, 1970). Rummel (1970) suggests that researchers should err on the side of overfactoring, rather than extracting too few components. However, in the light of the inability to obtain a suitable interpretable structure with four or more components, it is argued that the inclusion of more components is not viable. In addition, it could be argued that the three component solution provides a clear higher order structure explaining the impact of parental cancer on adult children.

At this point, it was decided that additional analyses on only the perceived benefit items might be prudent to determine whether their consistent failure to load as separate, conceptually distinct factors was in some way due to the influence of the negative items on the PCQ (i.e., that the negatively worded items were in some way impacting on how the benefit items fell out in the factor loadings). This course of action was deemed important, as the focus of the thesis is on perceived benefit finding and, therefore, it was imperative to ensure that the structure of the scale used to measure this variable was a true representation of this key concept.

Using principle components analysis, the benefits items only were analysed, using the same order of item deletion as outlined above, with the analysis instructed to create four factors (as suggested from the data obtained in Study One). The four component structure for the benefits items is demonstrated in Table 7.2. The four extracted components are representative of the four benefit themes derived from the data in Study One, however, the theme of personal development has emerged to only include items relating to the participants’ attitude to health and health behaviours, and therefore has been renamed health focus (HF).
Table 7.2
Component Loadings for Exploratory Principal Components Analysis with Direct Oblimin Rotation of Benefit Items from the Parental Cancer Questionnaire

<table>
<thead>
<tr>
<th>Item</th>
<th>AP</th>
<th>SPB</th>
<th>HF</th>
<th>FRB</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. As a result of my parent’s cancer I re-evaluated my career path</td>
<td>.83</td>
<td>.25</td>
<td>.20</td>
<td>.23</td>
</tr>
<tr>
<td>16. I have been more willing to try new things since my parent was diagnosed with cancer</td>
<td>.85</td>
<td>.26</td>
<td>.39</td>
<td>.34</td>
</tr>
<tr>
<td>17. I have achieved a better balance between work/study and home since my parent has had cancer</td>
<td>.82</td>
<td>.20</td>
<td>.37</td>
<td>.27</td>
</tr>
<tr>
<td>1. I became closer to my sick parent during his/her cancer</td>
<td>.26</td>
<td>.93</td>
<td>.13</td>
<td>.27</td>
</tr>
<tr>
<td>2. I have gotten to know my sick parent on a more meaningful level</td>
<td>.26</td>
<td>.92</td>
<td>.14</td>
<td>.39</td>
</tr>
<tr>
<td>23. As a result of my parent’s cancer I now engage in activities that help me reduce my own risk of getting cancer</td>
<td>.34</td>
<td>.18</td>
<td>.93</td>
<td>.22</td>
</tr>
<tr>
<td>24. I value my own health more since my experience of parental cancer</td>
<td>.36</td>
<td>.10</td>
<td>.94</td>
<td>.16</td>
</tr>
<tr>
<td>7. My relationship with my healthy parent improved as a result of my parent’s cancer</td>
<td>.24</td>
<td>.28</td>
<td>.22</td>
<td>.84</td>
</tr>
<tr>
<td>8. My relationship with at least one of my siblings improved as a result of my parent’s cancer</td>
<td>.31</td>
<td>.31</td>
<td>.10</td>
<td>.81</td>
</tr>
</tbody>
</table>

Variance explained: 37.3 17.5 12.4 10.5

AP = Altered Priorities, SPB = Sick Parent Benefits, HF = Health Focus, FRB = Family-Related Benefits

As can be seen from Table 7.2 the significantly shortened benefit content (from a possible 25 items to nine) raises issues relating to scale depth and content validity. Three of the four components have only two items, with the reminder including only three items. The family-related benefits subscale items relate to the healthy parent and siblings, however, both items could be irrelevant to individuals who had already lost one parent and had no siblings. Reliability analyses were performed, and it was found that, while three of the four subscales were reliable (with Cronbach alpha co-efficients in excess of .70), the family related benefits subscale had a
Cronbah’s alpha of .53, suggesting that this is unreliable (Garson, 2010). After consideration of the above points, the qualitative interpretability of the components, and the loss of depth in the description of possible benefits (and subsequent loss of content validity), it was decided that separating the benefit items from the negative items to create a separate scale was not suitable, and that rather the three component structure (parental cancer benefits, emotional experiences, and caregiver strain) suggested in the previous analysis was the best representation of The PCQ’s structure.

7.2 Reliability and Validity of the PCQ

This section assesses the reliability of the PCQ and presents data to support the validity of the measure. Table 7.3 presents Pearson correlations with other scales designed to assess the PCQ’s convergent and discriminant construct validity, along with subscale reliabilities. The internal reliabilities of the PCQ subscales are strong, with Cronbach alphas ranging from .87-.91. Alpha values such as these indicate a level of reliability that exceeds the minimum standards for exploratory research, and are indicative of reliability values of a good scale (Garson, 2010).

Pearson correlations shown in Table 7.3 allow an assessment of the convergent and discriminant validity of the PCQ. Convergent validity refers to the degree to which theoretically similar measures are related (i.e., that two tests which purport to measure the same concept, such as benefit finding, are related; Trochim, 2006). Discriminant validity refers to the degree to which theoretically dissimilar measures are not related (i.e., that two tests which purport to measure different concepts, such as benefit finding and loss, are unrelated; Trochim, 2006). Both types of validity go some way to establishing the PCQ’s construct validity as a suitable measure of the experience of parental cancer.
Table 7.3
*Summary of Pearson Correlations for Scores on the PCQ subscales, PTGI, CADI, CASI, RDCQ subscales and GDI-C and Cronbach alpha reliabilities.*

<table>
<thead>
<tr>
<th>PCQ Subscale</th>
<th>PTGI</th>
<th>CADI</th>
<th>CASI</th>
<th>RDCQ-D</th>
<th>RDCQ-C</th>
<th>GDI-C</th>
<th>Cron Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental Cancer Benefits</td>
<td>.44 **</td>
<td>.11</td>
<td>.20 **</td>
<td>-.14 *</td>
<td>.04</td>
<td>.09</td>
<td></td>
</tr>
<tr>
<td>Emotional Experiences</td>
<td>.30 **</td>
<td>.32 **</td>
<td>.16 *</td>
<td>-.68 **</td>
<td>.01</td>
<td>.63 **</td>
<td>.89</td>
</tr>
<tr>
<td>Caregiver Strain</td>
<td>.18 **</td>
<td>.52 **</td>
<td>.08</td>
<td>-.24 **</td>
<td>-.06</td>
<td>.40 **</td>
<td>.87</td>
</tr>
</tbody>
</table>

PCQ = Parental Cancer Questionnaire; PTGI = Posttraumatic Growth Inventory; CADI = Carers Assessment of Difficulties Index; CASI = Caregiver Assessment of Satisfactions Index; RDCQ-D = Reaction to Diagnosis of Cancer – Distress subscale; RDCQ-C = Reaction to Diagnosis of Cancer – Confrontation subscale; GDI-C = Grief Diagnostic Instrument; Cron Alpha = Cronbach’s Alpha

* p < .05, ** p < .01

The analysis of the PCQ’s convergent and discriminant validity is promising, with numerous significant correlations with other measures in the anticipated direction. There are weak to moderate positive correlations for all subscales of the PCQ with the well-validated and widely used measure of posttraumatic growth, the PTGI. Importantly, the strongest correlation was between the benefits subscale of the PCQ and the PTGI (r = .44), suggesting that the two scales are measuring a theoretically similar or related construct. The significant correlations between the PTGI and the other subscales of the PCQ (r = .30 and .18) are also suggestive that the relationships observed in the data from Study One have been confirmed in Study Two. Specifically, this pattern of findings is that higher level of benefits arises if there is a strong emotional reaction to the experience of parental cancer, and/or involvement in caregiving (as indicated by the presence of caregiver strain).

14 The negative correlations between the RDCQ-D and PCQ subscales may appear at first counterintuitive, as it would be expected that emotional experiences and caregiver strain would correlate in a positive manner with the distress reactions at diagnosis. However, the way the RDCQ is scored is that distress items are reverse scored, so that higher scores indicate lower levels of distress reactions. Therefore, a negative correlation does represent a relationship between the two scales in the anticipated manner (i.e., higher levels of distress are associated with higher levels of benefit finding, higher reported emotional responses, as suggested by the emotional experiences subscale and higher levels of caregiver strain).
In terms of subscale validity, weak correlations were found between the parental cancer benefits subscale and carer satisfaction index, while a non-significant result was found between benefits and carer difficulties. These findings support the convergent and discriminant validity of the benefits subscale. We would expect that caregiver satisfaction may contribute to overall benefit finding, while caregiver difficulties may minimise the opportunity to find positive aspects in the experience.

For the emotional experiences subscale, there is also evidence of convergent validity, with stronger significant correlations found between this subscale and distress reactions at diagnosis \((r = .68)\) and the grief measure \((r = .63)\). A non-significant relationship was found between this subscale and the confronting reaction to diagnosis scale, supporting the subscale’s discriminant evidence. The anticipated non-significant relationship between this subscale and carer satisfaction was not evident \((r = .16, p < .05)\). Whilst this may raise questions about the discriminant validity of the emotional experiences subscale, the degree of relationship between the two scales is considered very weak, and therefore no firm conclusion should be drawn.

Finally, there was evidence of the convergent validity of the caregiver strain subscale of the PCQ, with a moderate significant correlation between that subscale and the carer difficulties measure \((r = .52)\). The anticipated significant positive relationships between caregiver strain and the grief scale \((r = .40)\) and the distress reactions at diagnosis \((r = .24)\) were also found.

Also of note is that no significant relationships were observed between confronting reactions and the PCQ subscales. It was anticipated that there would be a significant positive relationship between the benefit finding subscale and the confrontation reactions, as confronting reactions are argued to represent psychologically healthier responses and a more positive way of viewing the cancer experience (Frank-Stromborg, 1989). Additionally, a significant negative relationship was expected between the emotional experiences identified in the PCQ and confronting responses, as
one subscale measures negative emotions, whilst the other purports to measure positive reactions. Such relationships were not confirmed in the current data.

In summary, this chapter has outlined the process undertaken to determine the component structure of the PCQ via principal components analysis. The originally conceptualised structure, based on the seven qualitative themes from Study One, was unable to be obtained, and a final analysis confirmed the presence of a three component structure. The PCQ contains three components: benefits from parental cancer (15 items), emotional experiences (11 items), and caregiver strain (7 items). All subscales of the PCQ demonstrate significant modest positive correlations with each other, and all subscales have reliability coefficients in excess of $\alpha = .85$. The final section of the chapter examined the relationships between the PCQ subscales and existing measures relevant to the study of the experience of parental cancer. Importantly, there is solid evidence to support the concurrent and discriminant validity of the PCQ as a suitable measure for use in relation to parental cancer. The following chapter now focuses on analyses examining the broad research aims and specific hypotheses proposed for Study Two.
Chapter 8: Study Two Results Relating to Research Aims and Hypothesis Testing

Once the structure of the PCQ was determined by principal components analysis, the focus of data analysis was directed at examining the research aims and specific hypotheses for Study Two. The current chapter reports the findings of a series of analyses designed to examine the prevalence of benefit finding, the types of benefits reported by adult children of cancer patients, while also examining variables that may be useful in the prediction of benefit finding. These initial data analyses indicated that an additional moderator analysis may be warranted. Finally, regression analyses designed to assess the predictive utility of benefit finding in relation to psychological outcomes are reported. The broad research aims and the specific hypothesis to be tested were:

Research Aim 1: To confirm the presence of perceived benefit finding in adults, whose parents have cancer, and examine the types of benefits that are reported by this cohort.

Specific hypotheses:
- 1.1. That benefit finding will be present in a sample of adult children of cancer patients.
- 1.2. That benefits relating to the sick parent and family will be the most frequently reported type of benefit.
- 1.3. That benefits relating to personal development will be the least frequently reported type of benefit.

Research Aim 2: To examine the role of negative experiential elements (i.e., emotional experiences and caregiver strain) and illness variables (e.g., parental gender, outcome of cancer) in predicting perceived benefit finding in the adult children of cancer patients.

Specific hypotheses:
- 2.1. That emotional experience (as measured by the emotional experiences subscale of the PCQ) would be predictive of benefit finding.
2.2. That involvement in caregiving (as measured by the caregiver strain subscale of the PCQ and 0-10 rating) would be predictive of benefit finding.
2.3. That the illness variables of a parent’s gender, the outcome of illness, and the time since diagnosis might assist in the prediction of benefit finding.

Research Aim 3: To examine the role of perceived benefit finding in the prediction of the mental health outcomes of depression, anxiety, stress and well-being arising from parental cancer.

Specific hypotheses:
3.1. That benefit finding, emotional experiences, and caregiving would be predictive of depression.
3.2. That benefit finding would not be predictive of anxiety, stress or well being; however, the variables of emotional experiences and caregiving would be predictive of those psychological outcomes.
3.3. Those individuals reporting high levels of benefit finding would differ from individuals with low levels of benefit finding in terms of depression.

Before commencing the reporting of specific hypothesis tests, the descriptive details of the main variables are presented. Table 8.1 provides the results of the descriptive and psychometric properties of the key variables used to test the study hypotheses in the subsequent analyses. Participants were asked to indicate their level of involvement in care on a scale of 0-10. The mean for this item was 4.51 ($SD = 3.49$), and the mode (excluding 0) was 7 ($n = 33$). Details of the illness-related variables used in the multiple regression analysis are outlined in the Study Two methodology chapter (see Section 6.2.1).
Table 8.1
Sample, Mean, Standard Deviation, Range and Skew of the Major Study Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
<th>Potential</th>
<th>Actual</th>
<th>Skew</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCQ – B</td>
<td>311</td>
<td>63.11</td>
<td>12.80</td>
<td>0-105</td>
<td>23-101</td>
<td>-.44</td>
<td></td>
</tr>
<tr>
<td>PCQ – E</td>
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<td>49.85</td>
<td>12.28</td>
<td>0-77</td>
<td>13-77</td>
<td>-.23</td>
<td></td>
</tr>
<tr>
<td>PCQ – C</td>
<td>311</td>
<td>25.43</td>
<td>9.24</td>
<td>0-49</td>
<td>0-49</td>
<td>.14</td>
<td></td>
</tr>
<tr>
<td>PTGI</td>
<td>301</td>
<td>34.53</td>
<td>22.88</td>
<td>0-105</td>
<td>0-102</td>
<td>.55</td>
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<tr>
<td>CADI</td>
<td>198</td>
<td>28.66</td>
<td>15.46</td>
<td>0-90</td>
<td>0-70</td>
<td>.09</td>
<td></td>
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<tr>
<td>CASI</td>
<td>193</td>
<td>51.51</td>
<td>17.10</td>
<td>0-90</td>
<td>3-85</td>
<td>-.56</td>
<td></td>
</tr>
<tr>
<td>RDCQ-D</td>
<td>291</td>
<td>64.79</td>
<td>17.27</td>
<td>0-95</td>
<td>21-95</td>
<td>-.30</td>
<td></td>
</tr>
<tr>
<td>RDCQ-C</td>
<td>291</td>
<td>23.19</td>
<td>8.44</td>
<td>0-45</td>
<td>9-45</td>
<td>.63</td>
<td></td>
</tr>
<tr>
<td>GDI-C</td>
<td>286</td>
<td>15.23</td>
<td>10.66</td>
<td>0-64</td>
<td>0-46</td>
<td>.73</td>
<td></td>
</tr>
<tr>
<td>DASS – Depression</td>
<td>290</td>
<td>6.67</td>
<td>8.92</td>
<td>0-42</td>
<td>0-42</td>
<td>1.75</td>
<td></td>
</tr>
<tr>
<td>DASS – Anxiety</td>
<td>290</td>
<td>4.76</td>
<td>7.23</td>
<td>0-42</td>
<td>0-38</td>
<td>2.09</td>
<td></td>
</tr>
<tr>
<td>DASS – Stress</td>
<td>290</td>
<td>9.69</td>
<td>9.77</td>
<td>0-42</td>
<td>0-42</td>
<td>1.13</td>
<td></td>
</tr>
<tr>
<td>WEMWBS</td>
<td>288</td>
<td>48.13</td>
<td>10.02</td>
<td>14-70</td>
<td>19-70</td>
<td>-.23</td>
<td></td>
</tr>
</tbody>
</table>

PCQ-B = Parental Cancer Questionnaire - Benefits subscale; PCQ-E = Parental Cancer Questionnaire - Emotional Experiences subscale; PCQ-C = Parental Cancer Questionnaire - Caregiver Strain subscale; PTGI = Posttraumatic Growth Inventory; CADI = Carers Assessment of Difficulties Index; CASI = Caregiver Assessment of Satisfactions Index; RDCQ-D = Reaction to Diagnosis of Cancer – Distress subscale; RDCQ-C = Reaction to Diagnosis of Cancer – Confrontation subscale; GDI-C = Grief Diagnostic Instrument; DASS = Depression, Anxiety and Stress Scale; WEMWBS = Warwick-Edinburgh Mental Well-being Scale

8.1 Confirming Benefit Finding and Examining the Types of Benefits Arising from Parental Cancer

The first research aim was to examine if the assertion that benefit finding may be possible in response to parental cancer would be confirmed, and to increase the current understanding of the types of benefits reported. To address this aim, four key pieces of information were examined: (a) the mean score on the PTGI; (b) the mean score on the benefit finding subscale of the PCQ (for points (a) and (b) see Table 8.1 above); (c) the prevalence of benefit finding in the sample (determined by the percentage of participants reporting benefits on both the PTGI and the PCQ-B); and (d) an examination of item means on the PCQ-B to determine which benefits were being strongly endorsed.
In terms of the prevalence of benefit finding, according to the PTGI, 98% \((n = 294)\) of the sample reported at least one benefit\(^{15}\), with the mean number of benefits reported being 13.36 \((SD = 6.27)\), and the modal number of benefits being 21 (i.e., all items on the PTGI endorsed). Of the 98% of participants endorsing items on the PTGI, 16% indicated that they felt the magnitude of their change was very small to small (i.e., only using the 1 or 2 response options), suggesting that 72% of the sample reported at least a moderate level of beneficial change, in at least one area. Ninety percent of the sample reported five or more benefits, while 69.5% endorsed 10 or more items on the PTGI. When measuring benefits using the PCQ-B, 95% \((n = 295)\) of the sample reported at least one benefit, with the mean number of benefits being 6.32 \((SD = 3.54)\), and the modal number of benefits being 4. Sixty-five percent of the sample reported five or more benefits, while 14% reported deriving 10 or more benefits from their experience with parental cancer. Differences in the mode and proportion of participants reporting five or more benefits is most likely to be due to the different response options utilised by each measure (i.e., the PCQ-B contains response options where participants can disagree with the suggested benefit outcome, while the PTGI is answered with options indicating incremental degrees of change), and the more generalised item content of the PTGI.

To examine the types of benefits being endorsed, an examination of item means was conducted for the PCQ-B\(^{16}\). Additionally, as there is some suggestion in the patient and spousal literature that there may be gender differences in the types of benefits reported, item means were obtained for each gender (see Table 8.2). An ANOVA was conducted to determine if there were gender differences in terms of either total benefits or specific benefit items. The ANOVA found that there was only one gender-based difference, with women reporting significantly higher levels of changes to their spirituality compared to men \(F (1, 301) = 7.97, p < .01\).

\(^{15}\) A response of 1 or more on any PTGI item was taken to indicate benefit finding.

\(^{16}\) An examination of item means was only performed on the PCQ-B, as it has been derived from data provided by adults, whose parents have cancer, and therefore was determined to be potentially more relevant to the target cohort than the items on the PTGI.
<table>
<thead>
<tr>
<th>Item</th>
<th>Total (SD)</th>
<th>Females (SD)</th>
<th>Males (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I became closer to my sick parent during their cancer</td>
<td>5.20 (1.30)</td>
<td>5.24 (1.31)</td>
<td>5.04 (1.25)</td>
</tr>
<tr>
<td>2. I have gotten to know my sick parent on a more meaningful level</td>
<td>4.86 (1.30)</td>
<td>4.91 (1.31)</td>
<td>4.63 (1.27)</td>
</tr>
<tr>
<td>3. Communication between my sick parent and I improved</td>
<td>4.62 (1.33)</td>
<td>4.68 (1.34)</td>
<td>4.38 (1.27)</td>
</tr>
<tr>
<td>4. My sick parent and I enjoyed a broader range of activities together after they were diagnosed</td>
<td>3.98 (1.32)</td>
<td>4.02 (1.34)</td>
<td>3.77 (1.18)</td>
</tr>
<tr>
<td>5. I developed a greater respect for my sick parent as a result of their cancer experience</td>
<td>5.25 (1.35)</td>
<td>5.30 (1.32)</td>
<td>5.00 (1.48)</td>
</tr>
<tr>
<td>6. My parent’s cancer gave me a chance to resolve past problem/s with my sick parent</td>
<td>3.81 (1.36)</td>
<td>3.89 (1.37)</td>
<td>3.49 (1.31)</td>
</tr>
<tr>
<td>7. My relationship with my healthy parent improved as a result of my parent’s cancer</td>
<td>4.27 (1.37)</td>
<td>4.30 (1.48)</td>
<td>4.15 (1.10)</td>
</tr>
<tr>
<td>8. My relationship with at least one of my siblings improved as a result of my parent’s cancer</td>
<td>4.28 (1.46)</td>
<td>4.29 (1.49)</td>
<td>4.19 (1.34)</td>
</tr>
<tr>
<td>9. My relationship with other family members (e.g., spouse, own children, uncle, grandparents) improved as a result of my parent’s cancer</td>
<td>4.16 (1.24)</td>
<td>4.11 (1.28)</td>
<td>4.38 (1.00)</td>
</tr>
<tr>
<td>10. I have a greater sense of connection with my family since my parent was diagnosed with cancer</td>
<td>4.48 (1.27)</td>
<td>4.47 (1.28)</td>
<td>4.54 (1.34)</td>
</tr>
<tr>
<td>12. Since my parent was diagnosed with cancer I make an effort to spend more time with family</td>
<td>4.91 (1.17)</td>
<td>4.93 (1.16)</td>
<td>4.81 (1.20)</td>
</tr>
<tr>
<td>15. My parent’s cancer changed my outlook on life for the better</td>
<td>4.43 (1.32)</td>
<td>4.48 (1.31)</td>
<td>4.23 (1.32)</td>
</tr>
<tr>
<td>16. I have been more willing to try new things since my parent was diagnosed with cancer</td>
<td>4.19 (1.19)</td>
<td>4.22 (1.19)</td>
<td>4.06 (1.16)</td>
</tr>
<tr>
<td>17. I have achieved a better balance between work/study and home since my parent has had cancer</td>
<td>4.10 (1.21)</td>
<td>4.09 (1.19)</td>
<td>4.12 (1.30)</td>
</tr>
<tr>
<td>21. I have developed an enhanced sense of spirituality as a result of my parent’s cancer</td>
<td>3.65 (1.50)</td>
<td>3.76 (1.47)</td>
<td>3.13* (1.52)</td>
</tr>
</tbody>
</table>

**TOTAL BENEFIT FINDING SCORE**

<table>
<thead>
<tr>
<th></th>
<th>Total (SD)</th>
<th>Females (SD)</th>
<th>Males (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>63.11 (12.80)</td>
<td>63.46 (12.95)</td>
<td>61.26 (12.13)</td>
</tr>
</tbody>
</table>

Responses on the PCQ-B are recorded using a 7-point Likert scale, with higher ratings indicating stronger endorsement of the benefit item. Item means less than four indicate disagreement with the suggested benefit.

* $p < .01$. 

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8.2 Predicting Benefit Finding

Prior to regression analysis, correlations between the involved variables were calculated, with the results presented in Table 8.3. As can be seen from the table, none of the relationships between variables exceed .90, and therefore the multicollinearity assumption for multiple regression has not been violated (Field, 2009; Tabachnick & Fidell, 2007). Correlations between selected illness variables and PCQ subscales were also calculated. Specifically, benefit finding was not significantly correlated with the gender of the sick parent \((r = -.05)\), the outcome of parental cancer \((r = -.01)\), or the duration of the parental illness \((r = .05)\). Emotional experiences was significantly correlated with the outcome of parental cancer \((r = .37, p < .01)\), but was not significantly correlated with the gender of the sick parent \((r = -.03)\), or the duration of the illness \((r = -.11)\). Finally, caregiver strain was significantly correlated with the outcome of parental cancer \((r = .17, p < .01)\), but not with the gender of the sick parent or the duration of the illness \((r = .11, \text{ and } r = .04 \text{ respectively})\).

Hierarchical multiple regression was used to assess the predictors of benefit finding, initially using the PTGI as the dependent variable, with the analysis then repeated using the PCQ-B as the dependent variable. Both analyses aimed to determine whether emotional reactions/experiences (measured by the emotional experiences subscale of the PCQ) and involvement in care (measured by 0-10 involvement in care item, and caregiver strain subscale of PCQ) were predictive of benefit finding, after controlling for selected illness variables and the other measures used in the study.

The initial hierarchical multiple regression with the PTGI as the dependent variable, was conducted to include the PCQ-B as an independent variable to further demonstrate the relationship between the two measures, and to assess the suitability of using the PCQ-B as the main measure of benefit finding in the remaining analyses in the study. The PCQ-B was entered at the final step in the analysis in order to assess if the new measure of benefit had predictive power over and above all other relevant variables.
<table>
<thead>
<tr>
<th>Measure</th>
<th>1</th>
<th>2</th>
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<th>10</th>
<th>11</th>
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<th>13</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Benefits</td>
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<td>2. Emotional experiences</td>
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<td>3. Caregiver strain</td>
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<td>4. Posttraumatic growth</td>
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<td>5. Carer difficulties</td>
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<td>6. Carer satisfaction</td>
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<td>7. Diagnosis - distress reaction</td>
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<td>8. Diagnosis - Confrontation reaction</td>
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<td>9. Grief</td>
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<tr>
<td>11. Anxiety</td>
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<tr>
<td>12. Stress</td>
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<tr>
<td>13. Well-being</td>
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<td>14. 0-10 Care</td>
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</table>

* p < .05, ** p < .01
Preliminary analyses were conducted to test for violations of the assumptions involved in multiple regression. Specifically, stem and leaf plots and box plots helped identify univariate outliers in the dependent variable, which were altered to scores +/- three standard deviations from the mean (Field, 2009). The required sample size was calculated, based on the formula outlined by Tabachnick and Fidell (2007) of \( N > 50 + 8 \) cases per IV, suggesting a minimum sample size of 154 was required. While the sample size varied in some cases, overall the sample size was sufficiently large (\( n = 311 \)). There are some issues with normality in most of the independent variables (i.e., significant results returned for Shapiro-Wilks and Kolmogorov-Smirnov tests), however Tabachnick and Fidell (2007) note that both tests can be overly sensitive. Visual examinations of the variables note that the problems with normality relate to positive or negative skew. However, when examining the nature of the variables, it is argued that they represent psychological constructs which would not be expected to be normally distributed in the general population. For example, the variable showing the greatest level of skewness is the total loss score (skewness = .73), suggesting considerable positive skew, or a higher proportion of low scores. However, when considering the construct being measured, low scores are actually indicative of higher levels of mental health, or better adjustment to one’s loss, as would be expected in a sample (i.e., we would anticipate that most individuals would adapt to their loss, with a smaller number reporting higher levels of distress). Inspection of the normal probability plot of standardised residuals against standardised predicted values indicated that, while there were deviations from normality, they were not severe (Tabachnick & Fidell, 2007). Therefore, no variable transformations were undertaken to correct normality issues. Mahalanobis distance for the critical \( \chi^2 \) for \( df = 13 \) (at \( \alpha = .001 \)) of 34.53 was violated by two cases, suggesting the presence of multivariate outliers. The analysis was re-run with the exclusion of the cases; however, no differences in the results were obtained, so they have been retained. The singularity assumption was met, and high tolerance scores and low variance inflation factor scores (VIF) for the predictor variables indicate that multicollinearity is not a concern.
Table 8.4 highlights the order of entry of variables and findings from the initial regression analysis using the PTGI as the dependent variable. In performing the hierarchical multiple regression, gender and submission type (online vs. mail) were entered into Block 1 to control for the effect of these variables. Preliminary analyses had suggested that there were differences based on gender or submission type for some of the other independent variables used in the regression analysis. Block 2 included illness variables (i.e., which parent was diagnosed with cancer, outcome of the cancer, duration of the cancer) and total scores for measures that had been used to assess PCQ validity. Block 3 included the benefit finding subscale of the PCQ, the two negative subscales from the PCQ (i.e., emotional experiences and caregiver strain) and the involvement in care item. The order of variable entry was determined in order to allow results to demonstrate what the key variables identified Study One, and reflected in the PCQ subscales, add to the prediction of benefit finding over and above the control variables and existing measures (Tabachnick & Fidell, 2007).

On the first step of the hierarchical multiple regression analysis, gender and submission type accounted for 4.2% of the variance in benefit finding (as measured by the PTGI), $F(2,184) = 4.02$, $p < .05$, with submission type being the significant predictor. On step 2, gender of parent, outcome of illness, duration of illness, CADI, CASI, RDCQ-D, RDCQ-C, and GDI-C were added to the regression equation, and accounted for an additional 33% of the variance in benefit finding, $\Delta F(8,176) = 11.56$, $p < .001$. Within this model, the significant predictors of benefit finding were CASI, RDCQ-D, and RDCQ-C. On step 3, PCQ-B, PCQ-E, PCQ-C and 0-10 involvement in care were added to the regression equation, and accounted for an additional 13.6% of the variance in benefit finding, $\Delta F(4,172) = 11.83$, $p < .001$. In combination, the 14 predictor variables explained 50.7% of the variance in benefit finding, $R^2 = .507$, adjusted $R^2 = .467$, $F(14,172) = 12.66$, $p < .001$. 
Table 8.4

Hierarchical Multiple Regression Analyses Predicting Benefit Finding (PTGI) From Demographic, Illness and Scale Variables

<table>
<thead>
<tr>
<th>Step</th>
<th>Variable</th>
<th>B</th>
<th>β</th>
<th>sr²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Gender</td>
<td>5.20</td>
<td>.09</td>
<td>.007</td>
<td>0.042*</td>
</tr>
<tr>
<td></td>
<td>Submission type</td>
<td>10.40</td>
<td>.19**</td>
<td>.035</td>
<td></td>
</tr>
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<td>2</td>
<td>Gender</td>
<td>.77</td>
<td>.01</td>
<td>.001</td>
<td>0.330**</td>
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<tr>
<td></td>
<td>Submission type</td>
<td>4.12</td>
<td>.07</td>
<td>.005</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Parent’s gender</td>
<td>-.96</td>
<td>-.02</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Outcome of illness</td>
<td>1.32</td>
<td>.08</td>
<td>.004</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Duration of illness</td>
<td>-.16</td>
<td>-.01</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td></td>
<td>CADI</td>
<td>-.11</td>
<td>-.07</td>
<td>.004</td>
<td></td>
</tr>
<tr>
<td></td>
<td>CASI</td>
<td>.53</td>
<td>.39**</td>
<td>.108</td>
<td></td>
</tr>
<tr>
<td></td>
<td>RDCQ-D</td>
<td>-.27</td>
<td>-.20*</td>
<td>.020</td>
<td></td>
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<tr>
<td></td>
<td>RDCQ-C</td>
<td>.45</td>
<td>.17*</td>
<td>.021</td>
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</tr>
<tr>
<td></td>
<td>GDI-C</td>
<td>.15</td>
<td>.07</td>
<td>.002</td>
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<tr>
<td>3</td>
<td>Gender</td>
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<td>-.01</td>
<td>.001</td>
<td>0.136**</td>
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<td></td>
<td>Submission type</td>
<td>4.83</td>
<td>.09</td>
<td>.007</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Parent’s gender</td>
<td>-.32</td>
<td>-.01</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Outcome of illness</td>
<td>2.20</td>
<td>.13</td>
<td>.011</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Duration of illness</td>
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<td>.002</td>
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</tr>
<tr>
<td></td>
<td>CADI</td>
<td>-.20</td>
<td>-.14</td>
<td>.010</td>
<td></td>
</tr>
<tr>
<td></td>
<td>CASI</td>
<td>.44</td>
<td>.33**</td>
<td>.067</td>
<td></td>
</tr>
<tr>
<td></td>
<td>RDCQ-D</td>
<td>-.24</td>
<td>-.18*</td>
<td>.013</td>
<td></td>
</tr>
<tr>
<td></td>
<td>RDCQ-C</td>
<td>.56</td>
<td>.20**</td>
<td>.030</td>
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</tr>
<tr>
<td></td>
<td>GDI-C</td>
<td>.17</td>
<td>.08</td>
<td>.003</td>
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</tr>
<tr>
<td></td>
<td>PCQ-B</td>
<td>.66</td>
<td>.37**</td>
<td>.114</td>
<td></td>
</tr>
<tr>
<td></td>
<td>PCQ–E</td>
<td>-.13</td>
<td>-.07</td>
<td>.002</td>
<td></td>
</tr>
<tr>
<td></td>
<td>PCQ–C</td>
<td>.34</td>
<td>.14*</td>
<td>.011</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0-10 Involvement in care</td>
<td>-.20</td>
<td>.03</td>
<td>.001</td>
<td></td>
</tr>
</tbody>
</table>

CADI = Carers Assessment of Difficulties Index; CASI = Caregiver Assessment of Satisfactions Index; RDCQ-D = Reaction to Diagnosis of Cancer – Distress; RDCQ-C = Reaction to Diagnosis of Cancer – Confrontation; GDI-C = Grief Diagnostic Instrument; PCQ-B = Parental Cancer Questionnaire – Benefits; PCQ–E = Parental Cancer Questionnaire – Emotional Experiences; PCQ–C = Parental Cancer Questionnaire – Caregiver Strain.

* p < .05; ** p < .01
Unstandardised \((B)\) and standardised \((\beta)\) regression coefficients, squared semi-partial correlations \((sr^2)\) for each predictor on each step, and \(R^2\) square change \((\Delta R^2)\) for each step of the hierarchical multiple regression analysis are reported in Table 8.4. As can be seen in Table 8.4, the significant predictors of benefit finding, as measured by the PTGI in the final regression model, are (in order of magnitude) PCQ-B, CASI, RDCQ-C, RDCQ_D, and PCQ-C.

Importantly, the new benefit variable (i.e., the PCQ-B) predicted benefit finding over and above all other variables. In addition, the hierarchical multiple regression also indicated that the strongest predictor of benefit finding, as measured by the PTGI, was the benefit subscale of the PCQ. This provides support of the utility of the PCQ-B as a measure of posttraumatic growth outcomes within the context of parental cancer. While it appears that the two scales are measuring the same broad construct, it is argued that the content of the PCQ-B is more relevant, as the item content was derived from data provided by the target cohort, and the types of benefits included on the PCQ-B relate specifically to the parental cancer experience. Based on these results, the next step in determining the predictors of benefit finding specific to the parental cancer experience was to re-run the previous analysis using the PCQ-B as the dependent variable (see Table 8.5). On step 1 of the hierarchical multiple regression analysis, gender and submission type accounted for a non-significant \(0.07\)% of the variance in benefit finding, \(F(2,184) = 0.61, p > .05\). On step 2, gender of parent, outcome of illness, duration of illness, CADI, CASI, RDCQ-D, RDCQ-C, and GDI-C were added to the regression equation, and, while still non-significant, accounted for an additional \(6.5\)% of the variance in benefit finding, \(\Delta F(8,176) = 1.53, p > .05\). Within this model, the only significant predictor of benefit finding is CASI. On step 3, PCQ-E, PCQ-C and 0-10 involvement in care were added to the regression equation, and accounted for an additional \(8.2\)% of the variance in benefit finding, \(\Delta F(3,173) = 5.59, p < .001\). In combination, the 13 predictor variables explained \(15.3\)% of the variance in benefit finding, \(F(13,173) = 2.41, p < .01\). By Cohen’s (1988) conventions, a combined effect of this magnitude can be considered medium \((f^2 = .18)\).
Table 8.5

Hierarchical Multiple Regression Analyses Predicting Benefit Finding (PCQ-B) From Demographic, Illness and Scale Variables

<table>
<thead>
<tr>
<th>Step</th>
<th>Variable</th>
<th>B</th>
<th>( \beta )</th>
<th>( s^2 )</th>
<th>( \Delta R^2 )</th>
</tr>
</thead>
<tbody>
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<td>1</td>
<td>Gender</td>
<td>2.21</td>
<td>.07</td>
<td>.004</td>
<td>0.007</td>
</tr>
<tr>
<td></td>
<td>Submission type</td>
<td>1.51</td>
<td>.05</td>
<td>.002</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Gender</td>
<td>2.01</td>
<td>.06</td>
<td>.003</td>
<td>0.065</td>
</tr>
<tr>
<td></td>
<td>Submission type</td>
<td>.02</td>
<td>.00</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Parent’s gender</td>
<td>-.46</td>
<td>-.02</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Outcome of illness</td>
<td>-.93</td>
<td>-.10</td>
<td>.007</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Duration of illness</td>
<td>.36</td>
<td>.06</td>
<td>.003</td>
<td></td>
</tr>
<tr>
<td></td>
<td>CADI</td>
<td>.01</td>
<td>.01</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td></td>
<td>CASI</td>
<td>.17</td>
<td>.22***</td>
<td>.035</td>
<td></td>
</tr>
<tr>
<td></td>
<td>RDCQ-D</td>
<td>-.10</td>
<td>-.14</td>
<td>.010</td>
<td></td>
</tr>
<tr>
<td></td>
<td>RDCQ-C</td>
<td>-.11</td>
<td>-.08</td>
<td>.004</td>
<td></td>
</tr>
<tr>
<td></td>
<td>GDI-C</td>
<td>-.04</td>
<td>-.04</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Gender</td>
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<td>.003</td>
<td>0.082**</td>
</tr>
<tr>
<td></td>
<td>Submission type</td>
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<td>.04</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Parent’s gender</td>
<td>.03</td>
<td>.00</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Outcome of illness</td>
<td>-1.92</td>
<td>-.20*</td>
<td>.027</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Duration of illness</td>
<td>.41</td>
<td>.07</td>
<td>.004</td>
<td></td>
</tr>
<tr>
<td></td>
<td>CADI</td>
<td>-.02</td>
<td>-.02</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td></td>
<td>CASI</td>
<td>.18</td>
<td>.23**</td>
<td>.035</td>
<td></td>
</tr>
<tr>
<td></td>
<td>RDCQ-D</td>
<td>.05</td>
<td>.06</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td></td>
<td>RDCQ-C</td>
<td>-.09</td>
<td>-.06</td>
<td>.002</td>
<td></td>
</tr>
<tr>
<td></td>
<td>GDI-C</td>
<td>-.20</td>
<td>-.17</td>
<td>.011</td>
<td></td>
</tr>
<tr>
<td></td>
<td>PCQ–E</td>
<td>.44</td>
<td>.42**</td>
<td>.071</td>
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</tr>
<tr>
<td></td>
<td>PCQ–C</td>
<td>.07</td>
<td>.05</td>
<td>.002</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0-10 Involvement in care</td>
<td>.16</td>
<td>.04</td>
<td>.002</td>
<td></td>
</tr>
</tbody>
</table>

CADI = Carers Assessment of Difficulties Index; CASI = Caregiver Assessment of Satisfactions Index; RDCQ-D Reaction to Diagnosis of Cancer – Distress; RDCQ-C = Reaction to Diagnosis of Cancer – Confrontation; GDI-C = Grief Diagnostic Instrument; PCQ-B = Parental Cancer Questionnaire – Benefits; PCQ-E = Parental Cancer Questionnaire – Emotional Experiences; PCQ-C = Parental Cancer Questionnaire – Caregiver Strain.

* \( p < .05 \), ** \( p < .01 \)
Unstandardised (B) and standardised (β) regression coefficients, squared semi-partial correlations (sr²) for each predictor on each step, and R square change (ΔR²) for each step of the hierarchical multiple regression analysis are reported in Table 8.5. As can be seen in Table 8.5, the significant predictors of benefit finding in the final regression model are (in order of magnitude) PCQ-E, CASI, and outcome of illness.

Upon examination of the hierarchical multiple regression, it was noted that outcome of illness was a non-significant predictor of benefit finding at step 2; however, in step 3 it had become a significant predictor. This change suggested that there was an interaction occurring between the outcome of illness variable and the variables added at step 3. In the light of the theoretical foundation of trauma-related growth, it was deemed that the most likely interaction was occurring between the outcome variable (i.e., successful treatment vs. spreading/recurrence, vs. treatment ongoing vs. death) and the emotional experiences variable. Specifically, it was thought that the emotional experiences would be heightened depending on the outcome of illness, with the intensity of emotion reported being greater if a negative outcome, and particularly death, occurred.

A one-way between-groups analysis of variance (ANOVA) confirmed that there were significant differences between groups based on outcome of the parent’s cancer in terms of emotional experience $F(3, 305) = 16.11, p < .00$ (see Table 8.6 for means and standard deviations).

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Successful treatment</td>
<td>89</td>
<td>43.30</td>
<td>10.64</td>
</tr>
<tr>
<td>Treatment ongoing</td>
<td>25</td>
<td>47.23</td>
<td>12.68</td>
</tr>
<tr>
<td>Spreading and/or recurrence</td>
<td>30</td>
<td>51.20</td>
<td>10.17</td>
</tr>
<tr>
<td>Deceased</td>
<td>165</td>
<td>53.61</td>
<td>11.96</td>
</tr>
</tbody>
</table>
To measure the effect size of the overall difference, eta squared was calculated ($\eta^2 = 0.14$), and used to calculate an $f$ value for effect size, $f = 0.40$, which would be considered a large effect size (Cohen, 1988). Post-hoc comparisons, using Gabriel’s procedure (due to unequal group sizes), indicated that there was a significant difference between participants whose parents had been successfully treated and those whose parents’ had died (effect size Cohen’s $d = -.37$, or a small effect; Cohen, 1988), or whose parents had experienced a spreading or recurrence of their cancer ($d = -.78$, large effect). There was also a significant difference between the group whose parents were currently undergoing treatment and those whose parents had died ($d = -.30$, small effect). No additional between group differences were found.

In the light of the results of the hierarchical multiple regression for benefit finding and the ANOVA, it was determined that outcome of illness may be acting as a moderator variable in the prediction of benefit finding. Following the procedures outlined by Frazier, Tix, and Barron (2004), a moderator analysis using hierarchical multiple regression was performed. Specifically, three dummy variables were created to represent the categorical moderator variable of outcome. The continuous predictor variable of emotional experience was standardised using $z$ scores. These new variables were then used to create interaction terms to be entered in the second step of the analysis (Frazier et al., 2004). Table 8.7 shows the steps in the moderator analysis.
Table 8.7

*Moderated Regression Analysis Testing for Interactions Between Emotional Experiences and Outcome of Parental Cancer*

<table>
<thead>
<tr>
<th>Step</th>
<th>Variable</th>
<th>B</th>
<th>SE</th>
<th>β</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Emotional Experiences</td>
<td>3.93</td>
<td>.76</td>
<td>.31**</td>
<td>.081*</td>
</tr>
<tr>
<td></td>
<td>Outcome 1</td>
<td>3.62</td>
<td>1.74</td>
<td>.13*</td>
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<tr>
<td></td>
<td>Outcome 2</td>
<td>1.60</td>
<td>2.68</td>
<td>.03</td>
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<tr>
<td></td>
<td>Outcome 3</td>
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<tr>
<td>2</td>
<td>Emotional Experiences</td>
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<td>.21**</td>
<td>.014</td>
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<tr>
<td></td>
<td>Outcome 1</td>
<td>3.88</td>
<td>1.83</td>
<td>.14*</td>
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<td></td>
<td>Outcome 2</td>
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<td>2.71</td>
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<tr>
<td></td>
<td>Outcome 3</td>
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<td>2.48</td>
<td>.11</td>
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<tr>
<td></td>
<td>Emotional Experiences X Outcome 1</td>
<td>2.45</td>
<td>1.82</td>
<td>.10</td>
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<tr>
<td></td>
<td>Emotional Experiences X Outcome 2</td>
<td>2.54</td>
<td>2.65</td>
<td>.06</td>
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<tr>
<td></td>
<td>Emotional Experiences X Outcome 3</td>
<td>5.33</td>
<td>2.96</td>
<td>.11</td>
<td></td>
</tr>
</tbody>
</table>

Outcome 1 = successful treatment coded 1, all other outcomes coded 0, Outcome 2 = ongoing treatment coded 1, all other outcomes coded 0, Outcome 3 = recurrence or spreading coded 1, all other outcomes coded 0.

**p < .01, * p < .05

Overall, the moderator regression model explains 9.5% of the variance, \( F(3, 301) = 4.50, p < .001 \). It is, however, noted that the second step containing the interaction terms makes a non-significant contribution to the overall model. Unstandardised (\( B \)) regression coefficients (and their standard error) and standardised (\( \beta \)) regression coefficients for each predictor, and R square change (\( \Delta R^2 \)) for each step of the moderator analysis are reported in Table 8.7. As can be seen in Table 8.7, the significant predictors of benefit finding in the final regression model, are (in order of magnitude) emotional experiences, and Outcome 1. Note that this outcome variable represents successful treatment, or cure, against all other possible outcomes. None of the interaction terms were found to be significant predictors of benefit finding, suggesting that outcome does not moderate the relationship between emotional experiences and benefit finding in parental cancer.
8.3 Benefit Finding in the Prediction of Psychological Outcomes

The next series of analyses were conducted to examine the predictive utility of the PCQ subscales for psychological dysfunction and well-being. To estimate the proportion of variance in depression, anxiety, stress and well-being, which can be accounted for by benefit finding, emotional experiences and caregiver strain, a series of four standard multiple regression analyses were performed. Prior to analyses being performed, the assumptions for multiple regression were evaluated (as outlined above). As before, there were issues with normality, especially in the dependent variables of depression, anxiety and stress. However, as it may be argued that we would not expect such variables to be normally distributed within the population, no data transformations were conducted.\(^{17}\)

Mahalanobis distance for the critical \(\chi^2\) for \(df = 4\) (at \(\alpha = .001\)) of 18.47 was not violated, suggesting that there are no multivariate outliers. The singularity assumption was met, and correlations between variables did not exceed .90, indicating that multicollinearity was not a concern.

In the prediction of depression, all independent variables were significant, \(F(4, 285) = 16.36, p < .001\)^{18}. Anxiety was predicted by emotional experiences, caregiver strain and benefit finding, \(F(4, 285) = 8.27, p < .001\), while stress was predicted by emotional experiences and caregiver strain, \(F(4, 285) = 10.28, p < .001\). The proportion of variance accounted for in well-being is much less than in the negative emotional

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\(^{17}\) Extreme scores, which may be detected as outliers in the dependent variables were not changed, as it is the author’s belief that they represent clinically valid outcomes that may arise from having a parent with cancer. However, to assess their impact on the results, initial analyses were conducted prior to screening for outliers in the dependent variables. After this analysis, outliers were identified and changed to scores three standard deviations below or above the mean. Analyses were then repeated to determine the effect of outliers. The results were largely the same, and there are no significant differences between the raw data set and the data set without outliers. In the light of this finding, the raw data set complete with outliers was used in the reported analyses.

\(^{18}\) It is noteworthy that benefit finding is a significant predictor of depression, despite the correlation analysis revealing that there is a non-significant relationship between these two variables, \(r = -.05, p > .05\). In considering these results, it is suggested that benefit finding acts as a suppressor variable in the regression analysis predicting depression. Suppressor variables are those that appear to have no relationship to the dependent variable, but which, when included into multiple regression analysis, change the prediction value of the other predictor variables (Woolley, 1997). As there is some negligible correlation between benefit finding and depression, benefit finding is best conceptualised as an impure suppressor, in that it will exert some direct influence on the dependent variable, as well as an indirect influence, by accounting for some of the invalid variance of the other predictor variables with which it is moderately correlated (Woolley, 1997).
states, with only 5% of the variance explained by the predictor variables, $F(4, 283) = 3.72, p < .01$. Table 8.8 presents the results of all four analyses, including the unstandardised ($B$) and standardised ($\beta$) regression coefficients, squared semi-partial correlations ($sr^2$) for each predictor, and the $R^2$ and $F$ values for each model.

Table 8.8

PCQ Subscales and Involvement in Care as Predictors of Depression, Anxiety, Stress and Well-being

<table>
<thead>
<tr>
<th>Variable</th>
<th>$B$</th>
<th>$\beta$</th>
<th>$sr^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Predicting Depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PCQ- Benefits</td>
<td>-.11</td>
<td>-.16**</td>
<td>.024</td>
</tr>
<tr>
<td>PCQ – Emotional experience</td>
<td>.21</td>
<td>.29**</td>
<td>.069</td>
</tr>
<tr>
<td>PCQ – Caregiver strain</td>
<td>.17</td>
<td>.17**</td>
<td>.024</td>
</tr>
<tr>
<td>0-10 Involvement in care</td>
<td>.31</td>
<td>.12*</td>
<td>.013</td>
</tr>
<tr>
<td>$R^2 = .187$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$F = 16.36**$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Predicting Anxiety</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PCQ- Benefits</td>
<td>-.08</td>
<td>-.14</td>
<td>.018</td>
</tr>
<tr>
<td>PCQ – Emotional experience</td>
<td>.10</td>
<td>.17*</td>
<td>.022</td>
</tr>
<tr>
<td>PCQ – Caregiver strain</td>
<td>.15</td>
<td>.20**</td>
<td>.030</td>
</tr>
<tr>
<td>0-10 Involvement in care</td>
<td>.13</td>
<td>.06**</td>
<td>.003</td>
</tr>
<tr>
<td>$R^2 = .104$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$F = 8.27**$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Predicting Stress</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PCQ- Benefits</td>
<td>-.06</td>
<td>-.08</td>
<td>.005</td>
</tr>
<tr>
<td>PCQ – Emotional experience</td>
<td>.15</td>
<td>.19</td>
<td>.028</td>
</tr>
<tr>
<td>PCQ – Caregiver strain</td>
<td>.23</td>
<td>.22**</td>
<td>.038</td>
</tr>
<tr>
<td>0-10 Involvement in care</td>
<td>.20</td>
<td>.07**</td>
<td>.004</td>
</tr>
<tr>
<td>$R^2 = .126$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$F = 10.28**$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Predicting Well-being</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PCQ- Benefits</td>
<td>.06</td>
<td>.07</td>
<td>0.00</td>
</tr>
<tr>
<td>PCQ – Emotional experience</td>
<td>-.10</td>
<td>-.12</td>
<td>.005</td>
</tr>
<tr>
<td>PCQ – Caregiver strain</td>
<td>-.17</td>
<td>-.16*</td>
<td>.011</td>
</tr>
<tr>
<td>0-10 Involvement in care</td>
<td>.05</td>
<td>.02</td>
<td>.020</td>
</tr>
<tr>
<td>$R^2 = .050$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$F = 3.71**$</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PCQ = Parental Cancer Questionnaire

* $p < .05$, ** $p < .01$
The final hypothesis to be tested was that individuals high in benefit finding would differ from those low in benefit finding in terms of depression, anxiety, stress and well-being. Groups of low, average and high benefit finders were created using quartiles (the average group containing the middle two quartiles). Table 8.9 presents the means and SD for benefit finding groups on the psychological outcome variables.

Table 8.9

Descriptive Statistics for Depression, Anxiety, Stress and Well-Being Based on Benefit finding Groups

<table>
<thead>
<tr>
<th>Level of benefit finding</th>
<th>n</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>72</td>
<td>6.66</td>
<td>9.29</td>
<td>4.67</td>
<td>7.42</td>
<td>8.81</td>
<td>10.03</td>
<td>48.39</td>
<td>11.14</td>
</tr>
<tr>
<td>Average</td>
<td>136</td>
<td>6.26</td>
<td>7.64</td>
<td>4.11</td>
<td>5.87</td>
<td>9.25</td>
<td>9.31</td>
<td>47.89</td>
<td>10.08</td>
</tr>
<tr>
<td>High</td>
<td>71</td>
<td>4.86</td>
<td>6.79</td>
<td>3.96</td>
<td>5.44</td>
<td>9.48</td>
<td>8.51</td>
<td>48.91</td>
<td>7.80</td>
</tr>
</tbody>
</table>

A one-way between-groups multivariate analysis of variance (MANOVA) was performed to investigate the differences between levels of benefit finding in psychological dysfunction and well-being. Four dependent variables were used: depression, anxiety, stress, and well-being. Preliminary assumption testing was conducted and violations were noted in the area of normality, as identified in the negative affective dependent variables earlier. As MANOVA is reasonably robust to violations in normality (Pallant, 2007) and the clinical nature of the dependent variables, no transformations were undertaken. However, a more stringent \( p \) value was set at \( p = .01 \). Box’s Test of Equality of Covariance was greater than .001, \( p = .048 \), indicating that the assumption of homogeneity of variance-covariance matrices was not violated. Levene’s Test of Equality of Error Variance indicated that the assumption of equality of variance had been violated for well-being, depression and anxiety. This issue can be addressed by using a more stringent alpha level, and alpha of .01, as suggested above, is recommended (Tabachnick & Fidell, 2007). Additionally, in the light of the unequal sample size between groups, and the violations to assumptions noted above, it was determined that Pillai’s criterion would be used to interpret
multivariate significance, as this test is more robust (Tabachnick & Fidell, 2007). No significant differences were found between groups on any dependent variable, $F(8, 548) = 1.14, p = .34$.

In summary, the major findings of the study include that emotional experiences, carer satisfactions and the outcome of parental cancer were predictors of benefit finding in parental cancer, accounting for 15.3% of the variance in benefit finding. While the hierarchical regression analysis suggested that the outcome of parental cancer may moderate the relationship between emotional experience and benefit finding, moderator analysis failed to confirm this suggestion. In terms of the prediction of psychological outcomes, depression was predicted by emotional experiences, involvement in care, lower levels of benefit finding and higher levels of caregiver strain (18.7% of variance explained). Anxiety was predicted by emotional experience, caregiver strain and involvement in caring (10.4% of variance explained). Stress was predicted by higher levels of caregiver strain and greater involvement in caregiving (12.6% of variance explained). The only predictor of well-being was lower levels of caregiver strain (5% of variance accounted for). It is noted that these findings, while significant, do explain a relatively small amount of variance in the psychological outcome variables. No significant differences were found between individuals reporting high and low levels of benefits in terms of depression, anxiety, stress, and well-being.
Chapter 9: Discussion of Study Two Findings

The second study in this thesis extended the earlier qualitative work of Study One, and offered a quantitative examination of perceived benefit finding arising from parental cancer. The survey specifically sought to identify and quantify the types of benefits reported by adults whose parents have cancer, to determine what factors are predictive of benefit finding, and to determine the role of benefit finding in the prediction of psychological outcomes. In doing so, the study developed a series of items based on the findings in Study One, and then trialled the new Parental Cancer Questionnaire items with a moderate sized group of adult children whose parents had cancer. The development of the measure determined the component structure of the scale, and gathered initial psychometric data in relation to the instrument. The current chapter will review each of the key findings in relation to the existing literature, drawing out the implications for intervention and further research. The limitations and strengths of the research will also be noted.

9.1 Perceived Benefit Finding in Parental Cancer: Types of Benefits

The major aim of the thesis was to investigate whether perceived benefit finding is a potential outcome from the experience of having a parent with cancer. Both the qualitative and quantitative studies undertaken confirm that benefit finding is perceived to be an outcome in adults whose parents have cancer. Study One highlighted that perceived benefit finding emerges across multiple domains, which largely fit with the categories of growth proposed by Tedeschi and Calhoun (1995) and Thornton (2002; i.e., benefits associated with interpersonal relationships, life perspectives, and the self). Further insight into the types of perceived benefits that adult children gain can be found by examining the items on the benefit subscale of the PCQ. For example, the most strongly endorsed items on the benefit subscale include:

- I developed a greater respect for my sick parent as a result of their cancer experience,
- I became closer to my sick parent during their cancer,
Since my parent was diagnosed with cancer I make an effort to spend more time with family, I have gotten to know my sick parent on a more meaningful level, and Communication between my sick parent and I improved.

These items (and participant responses) clearly show benefit finding in this sample of adult children, thereby confirming hypothesis 1.1 of Study Two. The most prevalent benefits, as determined by the item mean scores, typically involve family, and especially the relationship between the sick parent and their adult child, which confirms hypothesis 1.2. This is also reflected in the findings of Study One, whereby the most detailed benefit related themes involved changes in family relationships, especially with one’s sick parent. Specifically, items endorsed in the PCQ benefits subscale appear to match the sub-themes of an enhanced relationship with the sick parent, respect and appreciation, and valuing family. However, as the content of the PCQ items was derived from the Study One interview data, it would be expected that there would be a high degree of overlap between the sentiments expressed in both studies. However, what is important in this pattern of findings is the degree to which such sentiments are expressed. In both studies, benefits relating to the relationship with the sick parent are the strongest topic to emerge, with altered views of family also appearing as an important change. Taken together, the combined data suggest that the most likely area of growth from the parental cancer experience is in relation to family.

Previous studies into posttraumatic growth and benefit finding in cancer spouses, caregivers (mixed spouse and adult child cohorts), and adult children provide partial support for this assertion. Numerous studies confirm that family-related benefits are a frequent outcome in family members of cancer patients. Dorval et al. (2005) found that the marital relationship was enhanced in breast cancer couples, and Gray et al. (2000) reported an increased sense of closeness and improved communication between cancer patients and their spouses. Keitel et al.’s (1990) review of cancer spouses found that cancer provided a catalyst for change, so that trivial aspects of
the relationship were put aside and greater focus was placed on the relational aspects of martial partnerships. In terms of adult children, existing qualitative data (e.g., Baxandall & Reddy, 1993; Oktay, 2005; Tarkan, 1999) all provide case examples in which improved family relationships are evident, especially in relationships with the sick parent. Specifically, there are case examples that demonstrate an increased closeness and connection between the child and sick parent (Baxandall & Reddy, 1993; Oktay, 2005), improved communication (Tarkan, 1999) and efforts to spend more time with family (Oktay, 2005, see Section 2.3.2 for greater detail).

The data from the two studies conducted in this thesis strongly suggest that family-related benefits are the greatest area of positive change in adults whose parents have cancer, and it is this degree of change that is unsupported by other studies. Specifically, in their study of cancer caregivers, Wong et al. (2009) identify personal strength as the strongest area of benefit, followed by enhanced relationships between carer and patient. Similarly, Manne et al. (2004) found that their sample of breast cancer spouses reported greatest growth in the domains of personal strength and new possibilities for life. These findings are in sharp contrast to the current study, as items on the PCQ reflecting personal growth were not strongly endorsed, and all but one failed to load on the final version of the scale. Furthermore in Study One, the theme of personal development was the weakest of themes, in that it was mentioned to a much lesser degree, and in less detail, than the sick parent and family-related themes. One possible explanation may be due to the gender breakdown of the current sample (82.5% female), as research with cancer patients has found that females typically report higher levels of benefits in the social relationships domain, while males report higher levels of benefits in the personal growth domain (Weaver et al., 2008). In contrast, spousal studies (e.g., Manne et al., 2004; Thornton & Perez, 2006) tend to find that women report higher levels of growth on all domains. Furthermore, a meta-analytic review investigating gender differences in relation to levels of self-reported posttraumatic growth across a variety of trauma events concluded that women generally report

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19 Due to the final version of the PCQ having only one personal development item, hypothesis 1.3, that personal development benefits would be the least reported area of growth, is unable to be directly tested.
higher levels of posttraumatic growth (Vishnevsky, Cann, Calhoun, Tedeschi, & Demakis, 2010). The current study found no gender differences in terms of the level of overall perceived benefit finding while, in terms of specific benefit items, significant gender differences were only noted on the spiritual development item, with women reporting greater levels of this type of benefit. The non-significant results for gender in the current sample suggest that gender may not be the primary explanation for the increased emphasis on family-related benefits, however, the great gender disparity is still an issue of concern (i.e., a greater percentage of male participants may have revealed some more gender differences). Another possible explanation is that the item content in the PCQ may be restricted, due to the lack of emphasis on personal development benefits in Study One (i.e., personal strength items that are studied in other research were absent from the present study). Alternatively, the increased emphasis on family-related benefits may represent a key point of difference with existing knowledge, and therefore it needs to be examined in future research before firm conclusions can be drawn.

The finding that perceived benefit finding was present in 95-98% of participants (dependent on the measure used) is further evidence supporting the contention that benefit finding is a frequent occurrence in family members facing the highly stressful situation of cancer (Leedham & Meyerowitz, 1999; Nolen-Hoeksema & Davis, 2004, Weiss, 2004). However, due to the study’s cross-sectional design, and the type of information obtained from participants, it is not possible to conclude whether the reported growth fits within the theoretical models of growth as a construction or illusion. Participation in the study was, however, restricted to adults whose parents had been diagnosed at least 12 months prior to participation and therefore, according to the Janus Face model (Maercker & Zoellner, 2004; Zoellner & Maercker, 2006), it is probable that the types of benefits reported reflect the outcome of posttraumatic growth (or construction), rather than a illusory coping response. Indeed, Maercker and Zoellner (2004) argue that constructive growth is assumed to increase over time, while illusory growth will decrease.
9.2 Predicting Benefit Finding

The second aim of Study Two was to examine the role of illness and experiential variables in the prediction of perceived benefit finding. The significant predictors of benefit finding in Study Two were emotional experiences, carer satisfactions, and the outcome of parental cancer. Specifically, benefit finding is likely to be higher amongst individuals who report greater emotional reaction or disturbance, and higher levels of care-related satisfactions. The predictive utility of the outcome variable is complex and will be discussed below. This finding confirms hypothesis 2.1, that emotional experiences would be predictive of benefit finding. Hypothesis 2.2, that involvement in caregiving (as measured by the 1-10 rating scale and the caregiver strain subscale of the PCQ) would be predictive of benefit finding is refuted. However, the finding that carer satisfaction is predictive of benefit finding suggests that the way in which involvement in care is conceptualised and measured may be relevant to predicting benefit finding. In the current study, involvement in care was measured by two variables, a 0-10 rating of involvement and the caregiver strain subscale of the PCQ, both of which were non-significant predictors. Carer satisfaction is still an indication of involvement in caregiving to one’s ill parent, but this finding suggests that simple involvement in caring is insufficient to bring forth benefit finding. Rather, adult child carers, who perceive the care experience as rewarding and satisfying, are more likely to report higher levels of benefits.

The finding that emotional experience is the strongest predictor of perceived benefit finding complements the existing knowledge of posttraumatic growth theory. Such theories argue that the stress situation must be severe enough to challenge the individual’s basic assumptions, if it is to prompt the changes to fundamental beliefs and trigger cognitive processing that gives rise to benefit finding (e.g., Janoff-Bulman, 1992; Tedeschi & Calhoun, 1995, 2004). The emotional experience subscale of the PCQ measures affective experience in both the short and long term in response to having a parent with cancer, and therefore provides a strong
measure of the nature of affective reaction to parental cancer. Those who report higher levels of emotional experiences are reporting intense reactions such as shock, trauma, devastation, and helplessness, which supports the argument that parental cancer would be considered a traumatic experience under Calhoun and Tedeschi’s (1999) broad definition of trauma. Such terms suggest that the stress associated with parental cancer would be sufficient to challenge previously held assumptions about the world, and therefore prompt growth, as the individual struggles to make sense of the event.

The finding that a higher emotional response is related to greater benefit finding is similar to the findings of the study by Mosher et al. (2006), examining adult daughters of breast cancer patients. Mosher et al. concluded that daughters, who perceived their mother’s illness as stressful, reported higher levels of posttraumatic growth. Weiss’ (2004) study of spouses also found that higher perceived stressfulness of the partner’s cancer was linked to higher posttraumatic growth in spouses. Together, the combined findings add weight to the contention by Thornton and Perez (2006) that cancer in a close family member represents real, first hand suffering, which shatters the individual’s world, thereby making them candidates for posttraumatic growth in their own right.

Satisfaction with the caregiving role was also identified as a significant predictor of benefit finding. To date, there has been little research examining the two concepts concurrently. The research which has been done by Foster, Kozachek, Stern, and Elsea (2010) suggests that there is a relationship between caregiver satisfaction and benefit finding, which in turn may influence overall well-being. In addition, a study by Walker, Shin, and Bird (1990), which examined daughters caring for their mothers, found that daughters who reported positive changes in their relationship with their mothers (i.e., benefit finding) also reported higher levels of caregiver satisfaction. Finally, Haley, LaMonde, Han, Burton, and Schonwetter (2003) found that greater benefit finding in the caregiving experience was linked to increased life satisfaction. Considering these findings and the predictive utility of carer satisfaction for benefit finding in Study Two, it is
suggested that there is a relationship between the two concepts, which may reflect the individual’s cognitive attempts to reinterpret stressful situations.

Despite the lack of research in the area of benefit finding and carer satisfaction, it seems intuitive that an individual, who is able to perceive the rewards in caregiving, would also be able to reconceptualise highly stressful situations and identify benefits arising from them. However, the degree to which this is entirely determined by cognitive factors is debated, and this finding may therefore be suggestive of the presence of broader personality or environmental variables that may underpin the ability to cognitively appraise stressful situations as potential positives. Two variables, which may account for this finding, are optimism and adequate social support, both of which previous research has suggested may contribute to posttraumatic growth. For example, Dunn et al. (2011) found that higher levels of benefit finding were present in cancer patients, who reported high levels of optimism and social support. Furthermore, the meta-analysis conducted by Prati and Pietrantoni (2009) concluded that social support and optimism were moderately correlated with posttraumatic growth. Specifically, Prati and Pietrantoni suggested that optimism relates to posttraumatic growth through threat appraisal and the use of adaptive coping strategies. Social support assists in the development of growth through several avenues including an increased likelihood of a favourable appraisal of the situation, an increased use of effective coping strategies, and providing perspectives through which individuals are able to construct narratives that give meaning to the events (Prati & Pietrantoni, 2009). However, neither optimism nor social support were measured in the present study, and therefore represent a potentially fruitful avenue for future research. Specifically, an investigation of the relationship between carer satisfaction and benefit finding, while controlling for optimism and social support, would enable researchers to examine the nature of the relationship between carer satisfaction and benefit finding.

The outcome of parental cancer (i.e., successful treatment vs. treatment ongoing, vs. recurrence/spreading vs. death) also emerged as a significant predictor of perceived benefit finding. This result provides
partial support for hypothesis 2.3, as the other illness variables (i.e., parent gender and duration of illness) were not predictive of benefit finding. The finding that illness outcome predicts benefit finding was unexpected, as the correlation analysis revealed a non-significant relationship between outcome of parental cancer and benefit finding \((r = .01, p > .05)\), and ANOVA analysis confirmed that there were no differences in the level of benefit finding based on outcome grouping \((F = .04, p > .05)\). When outcome was entered into the regression model at step 2, it was found to be a non-significant predictor, as would be expected by the correlation and ANOVA results. However, with the addition of the PCQ subscales at step 3, the outcome of parental cancer variable became a significant predictor of benefit finding. This suggested that there may be a moderating relationship occurring between outcome and one of the PCQ subscale variables, a view that would be supported by Coyne and Tennen (2010), who argue that moderator variables may contribute to the inconclusive findings with the field of posttraumatic growth. Considering that moderation analysis should be driven by theory (Frazier et al., 2004), reflection on posttraumatic growth theory seemed to suggest that the outcome of parental cancer may potentially moderate the relationship between emotional experiences and benefit finding. Specifically, it is suggested that a negative outcome (such as recurrence, spreading, or death) is more stressful, which in turn inflates scores on the emotional experiences variable, and therefore the interaction between these two variables changed the outcome of illness variable from a non-significant to a significant predictor of benefit finding in step 3. ANOVA analysis confirmed that individuals, whose parents died, reported higher emotional experiences compared to individuals whose parents were successfully treated or were still undergoing treatment. There was also a significant difference between individuals who reported a spreading or recurrence of their parents’ cancer and those whose parents were successfully treated.

A moderator analysis was conducted, and the interaction terms were found to be non-significant predictors of perceived benefit finding, suggesting that the overall outcome of parental cancer does not moderate the relationship between emotional experiences and benefit finding. However,
there are two noteworthy points that arise from this analysis. Firstly, in step 1 of the moderator analysis, the variable that represents parents being cured vs. all other outcomes is a significant predictor of benefit finding, and remains so when the interaction terms are introduced at step 2. Secondly, while none of the interaction terms are significant, one interaction term (emotional experiences X recurrence/spreading vs. all other outcomes) is approaching significance ($p = .07$). Taken together, these two points suggest that there may actually be some influence between the emotional experiences and outcome of illness variable in relation to benefit finding. However, sampling issues with Study Two (i.e., the overall sample size, large disparities in the number of participants in each illness outcome group) may have prevented the true relationship from being revealed.

Unfortunately, the relationship between outcome of illness, emotional experience and benefit finding is not clarified by the existing literature on death and benefit finding. In a study examining factors associated with complicated grief, Neimeyer, Baldwin, and Gillies (2006) found that benefit finding contributed to less separation and traumatic distress for bereaved individuals. Similarly, a study by Davis, Nolen-Hoeksema, and Larson (1998) found that higher levels of sense-making (of which benefit finding is a key component) were associated with lower distress, especially in the period following loss. In contrast to the findings of Davis et al. (1998), Michael and Snyder (2005) found that benefit finding was linked to lower levels of distress within the first 12 months of bereavement, but higher distress after 12 months of bereavement. These findings seem to contradict Study Two, which found that there were no differences in terms of benefit finding between bereaved and non-bereaved participants, despite the participants in the deceased group reporting higher levels of emotional disturbance. Based on the previous studies, it could have been argued that the bereaved group with higher distress reactions would have reported lower levels of benefits, but this pattern was not found. In the light of the points raised by the moderator analysis, the conflicting findings of existing literature, and the pattern of results in Study Two not matching previous research, the potential moderating effect of outcome of illness on emotional experiences and benefit finding is highlighted as an area requiring
additional research. This may be particularly pertinent to intervention programs, especially if the outcome of parental cancer does exacerbate the intensity of emotional reactions, as it suggests that additional support services should be offered to individuals who lose a parent to cancer, or whose parents experience a recurrence or spreading of the disease.

9.3 Benefit Finding in the Prediction of Psychological Outcomes

Study Two examined the predictive utility of perceived benefit finding in relation to depression, anxiety, stress and well-being, thereby fulfilling the third aim of the study. The results demonstrated that benefit finding was a significant inverse predictor of depression; however, benefit finding was a non-significant predictor of the other affective states, including well-being. In addition to benefit finding, depression was also predicted by emotional experiences, caregiver strain, and involvement in caregiving, therefore confirming hypothesis 3.1. This finding suggests that benefit finding may act as a protective factor, which may reduce the likelihood of a person developing depression, or reduce the severity of reported depression.

The results showing perceived benefit finding being predictive of depression is consistent with the work of several other researchers, who have found that posttraumatic growth and benefit finding are associated with lower levels of depression. For example, a longitudinal study by Carver and Antoni (2004) with breast cancer patients found that initially higher levels of benefit finding were predictive of lower depression at follow up (4-7 years post-diagnosis). There is also consistent evidence from HIV research (e.g., Littlewood, Vanable, Carey, & Blair, 2008; Updegraff, Taylor, Kemeny, & Wyatt, 2002) that benefit finding is linked to lower levels of depression in HIV patients. Furthermore, the meta-analysis conducted by Helgeson et al. (2006) examining 77 research articles on benefit finding and physical and mental health outcomes concluded that benefit finding is related to lower depression.

Considering that this thesis examines perceived benefit finding and its relationship to depression in family members, rather than the patient.
themselves, it is important to compare the current findings with other research on family members. A study by Mock and Boerner (2010) into patients with amyotrophic lateral sclerosis and their carers found that benefit finding was associated with lower depression levels for both patients and carers. In an extension of the benefit finding research, Kim, Schulz, and Carver (2007) examined six domains of benefit finding in relation to depression, and found that several domains of benefit finding demonstrated unique associations with depression. Specifically, overall benefit finding score was unrelated to depressive symptoms, but benefits relating to acceptance and self-view were linked to lower levels of depression, while benefits associated with empathy and a reprioritisation of life values were linked with greater depression. Taken together, the existing literature and the findings from Study Two provide evidence that benefit finding may play a role in reducing depression for adults whose parents have cancer.

It is, however, noted that the relationship between depression and benefit finding is not direct, and it is proposed that benefit finding may function as a suppressor variable in the current study. An alternate explanation is that there may be a moderating or mediating variable, which influences the predictive relationship between benefit finding and depression. Such a suggestion is supported by Coyne and Tennen (2010), who argued that moderator variables may influence the relationship between posttraumatic growth and adjustment. Existing research also tends to support the notion that posttraumatic growth may interact with other variables to influence psychological outcomes. For example, Morrill, Brewer, O’Neill, Lillie, Dees, Carey, and Rimer (2008) found a non-significant relationship between posttraumatic growth and depression. However, when they considered the interaction between growth and posttraumatic stress symptoms, they found the relationship between depression became significant. Specifically, the relationship between high PTSD symptoms and depression was reduced, when the interaction between posttraumatic growth and PTSD symptoms was included. Morrill et al. concluded that posttraumatic growth may be psychologically protective through its indirect relationship with depression, a finding that appears to be echoed in the current study. It is, therefore, strongly suggested that future
studies consider potential moderating variables that may enhance our understanding of the relationship between benefit finding and psychological outcomes such as depression.

In Study Two, perceived benefit finding was a non-significant predictor of anxiety, stress, and well-being, therefore partially supporting hypothesis 3.2. The non-significant finding in relation to anxiety was expected in the light of previous research, with most studies failing to find a significant relationship between the two. While more recent research has found a significant relationship, this newer research has included additional variables to enhance our understanding of the relationship between anxiety and posttraumatic growth. Specifically, Loiselle et al. (2011) distinguished between state and trait anxiety to find that lower trait anxiety was associated with posttraumatic growth in individuals, who had a family member with a serious illness, while state anxiety was unrelated to growth. In another study, Boals et al. (2010) examining the role of anxiety in events that bear significant importance to the individual’s identity (i.e., event centrality). In that study, the researchers limited analysis to traumatic events, which the participants identified as having a significant impact on their identity (i.e., they felt the event changed who they were). When this limitation was put in place, the correlation between anxiety and posttraumatic growth was found to be significant, and suggested that higher levels of posttraumatic growth are associated with lower levels of anxiety (Boals et al., 2010). The inclusion of variables, such as event centrality and trait vs. state anxiety, may prove valuable additions to future research in this area.

Despite it seeming intuitive that higher levels of benefit finding would be associated with higher levels of well-being, the current study failed to find a relationship between the two variables, and consequently benefit finding was not a significant predictor of well-being. This mirrors the argument by Janoff-Bulman (1992) that posttraumatic growth actually represents a change in the individual, described as being ‘wise but sad.’ Essentially, exposure to the trauma leads individuals to establish more realistic views of the world, but doing so highlights personal vulnerability, which may, in turn, lead to a decreased sense of well-being. This argument
is supported by research conducted by Janoff-Bulman (1992), which found that the assumptive worlds of trauma victims are more negative compared to non-victims.

When examining the empirical literature on posttraumatic growth and benefit finding in relation to well-being, the results are mixed, with several reviewers (e.g., Coyne & Tennen, 2010; Sumalla et al., 2009; Zoellner & Maercker, 2006) highlighting the inconsistencies in findings relating to well-being and growth. Thornton and Perez (2006) in their study of prostate cancer spouses found that quality of life was unrelated to benefit finding for both patients and spouses. Studies by both Cordova et al. (2001) and Urcuyo et al. (2005) have also reported that benefit finding is largely unrelated to well-being in breast cancer patients. On the other hand, Rinaldis, Pakenham, and Lynch (2010) found that benefit finding was predictive of higher positive affect and quality of life, 12 months post-diagnosis for colorectal cancer patients, while Mols et al. (2009) found that benefit finding was positively related to satisfaction with life. Greater satisfaction with life was also found to be related to benefit finding in family carers of cancer patients in the study by Kim et al. (2010). Two meta-analyses (Helgeson et al., 2006; Sawyer, Ayers, & Field, 2010) have been conducted into the area of growth/benefit finding and psychological outcomes in general (i.e., not limited to cancer research), and both reach the conclusion that there is a relationship between posttraumatic growth/benefit finding and well-being. Specifically, the meta-analyses by Helgeson et al. (2006) concluded that benefit finding was linked to positive well-being, and that the largest effect sizes for benefit finding were in relation to well-being, rather than depression. The review by Sawyer et al. (2010) also concluded that there is a small positive relationship between posttraumatic growth and positive mental health.

One possible explanation for the inconsistent findings on this topic may be due to how the concepts are conceptualised and measured. Well-being is often measured with quality of life measures or affect measures, in which low/nil levels of negative affect are seen to be indicative of well-being. For example, Carver and Antoni, (2004) measured well-being
through lower levels of negative affect, such as depression and distress, finding that benefit finding predicted well-being years after a diagnosis of breast cancer. Current conceptualisations of well-being would argue that it is not simply the absence of negative affect, but rather a multi-faceted concept that reflects individuals’ evaluations of multiple aspects of their lives (Diener, 2006; Paim, 1995), and as such is best measured by scales that are designed to specifically measure well-being (e.g., the WHO [Five] Well-being Index [World Health Organisation Collaborating Centre in Mental Health, 1998]; Warwick-Edinburgh Mental Well-being Scale [WEMWBS; Tennant et al., 2007]; General Well-being Index [Dupuy, 1984]).

There is also some suggestion that research design may influence findings, with longitudinal studies tending to find positive associations between benefit finding and well-being. For example, Schwarzer et al. (2006) found that overall benefit finding (gauged by the mean benefit finding score of the entire sample) was unrelated to well-being at any point over the 12 months of their study of cancer patients. However, they did find that a change in benefit finding, from low to high levels (measured by tracking change in benefit finding scores for participants grouped as low benefit finders at Time 1) did influence well-being. Finally, Sears et al. (2003) found that the simple identification of benefits (which they termed benefit finding) did not contribute to well-being, but the regular use of benefit-related information as a coping mechanism (which they termed positive reappraisal coping) did predict mental health. The findings of Schwarzer et al. (2006) and Sears et al. (2003) suggests that benefit finding may, in some way, influence well-being, that the mechanism of this influence is largely unknown, but the association may relate to how benefit-related knowledge is used by the individual.

In terms of the present findings, the failure to detect a relationship between benefit finding and well-being may also be related to the measures used (i.e., the PCQ is a new measure and the WEMWBS has not been used in cancer research). However, the limited existing research into the relationship between well-being and benefit finding in family members is
conflicted (e.g., Kim et al., 2007; Thornton & Perez, 2006), despite the use of well-validated measures, suggesting that issues with measures may not be the sole contributor to Study Two’s null findings in this area. It is also recognised that the majority of studies, which have found a positive relationship between well-being and benefit finding, have been conducted on the cancer patients themselves, and it is possible that children will report a different relationship between these variables. This area is therefore highlighted as an area of future investigation, with the recommendation that longitudinal designs be employed where possible.

Finally, the results of Study Two suggest that caregiver strain is a significant predictor of well-being, specifically that lower levels of strain were associated with higher levels of well-being. This finding is consistent with many studies examining care-giver strain and well-being (e.g., Haley et al., 2003; Han & Haley, 1999; Rees, O’Boyle, & MacDonagh, 2001; Wyller et al., 2003). Specifically, it has been found that caregiver strain has an inverse relationship with well-being, and that caregiver burden impacts on multiple aspects of caregiver well-being (i.e., physical, psychological and financial; Grov, Fossa, Sorebo, & Dahl, 2006; Hauser & Kramer, 2004). Importantly, Haley et al. (2003) found that, when caregivers appraise care-related tasks as stressful, they report higher levels of depression and reduced life satisfaction. Taken together, the findings of Study Two and the existing literature suggest that interventions, which deal with caregiver stress, are essential to improve the well-being of family care providers.

The final hypothesis for Study Two, hypothesis 3.3 was to confirm that individuals high in perceived benefit finding would differ from those low in perceived benefit finding in relation to depression. There is some support for perceived benefit finding influencing depression (i.e., that benefit finding is a significant predictor of lower levels of depression), however, the non-significant MANOVA finding, and the non-significant correlation between benefit finding and depression, seem to imply that benefit finding is best conceptualised as a suppressor variable, rather than having a direct relationship with depression. At this stage, no firm conclusions can be drawn, and future studies will need to clarify whether
benefit finding is a suppressor variable, a direct predictor of depression, or whether moderating or mediating variables influence this relationship. It is also recommended that future studies involve a longitudinal design to allow an investigation of whether the role of benefit finding on affective outcomes changes over time throughout the parental cancer experience.

9.4 The Parental Cancer Questionnaire (PCQ)

The final research aim for the thesis was to develop a reliable measure that examines multiple aspects of the parental cancer experience. The PCQ, examining (a) parental cancer benefits, (b) emotional experiences and (c) caregiver strain has been examined through the process of principal components analysis. In the scale’s development, it was originally conceptualised that there were four benefit subscales, reflecting the benefit themes that emerged from Study One. However, this structure was unsupported by the principal components analysis. Once the analysis had confirmed that the benefits items were best conceptualised as one united benefits subscale, the three component structure was examined, and in combination with the data from the pilot study, the following definitions are proposed for each component. The first component represents benefits arising from parental cancer, and is defined as positive changes that the individual attributes to be arising, at least in part, from having had a parent with cancer. The second component examines the emotional experiences commonly arising from having a parent with cancer, and is defined as the affective impact of having a parent with cancer, both during their illness and/or as a long term consequence of this illness. The third component represents caregiver strain, and is defined as negative changes and associated affective responses arising from involvement in caring for one’s sick parent. Participants do not need to be full-time carers to report levels of caregiver strain; rather, this component represents some level of involvement in care-giving, and may simply have been frequent visits to see the sick parent.

As this was the first time that the PCQ has been used in research, it is important to look at the characteristics of the subscales, and examine how they relate to both the qualitative data that was collected in Study One and
Study Two (i.e., open ended question at the ended of the survey). For the emotional experiences subscale the most strongly endorsed items were:

- My parent’s cancer has been a traumatic experience for me,
- I was shocked when my parent was diagnosed with cancer,
- I feel great sadness when I think about my parent’s cancer,
- I was devastated by my parent’s cancer, and
- I felt helpless when my parent was sick.

The emotional aspects of having a parent with cancer is by far the most mentioned topic in the qualitative comments provided with the survey submissions, with emotional difficulties being mentioned 45 times. Phrases, which were commonly used, included worry, guilt, anger, sad, scared, isolated, shock, traumatic, and helplessness. Several participants described it as an emotionally difficult time, while other participants suggested that they perceived the experience as the most challenging period in their life, using phrases such as “hardest thing I have done so far in my life” (Female participant, aged 31-35) and “the scariest time of my life” (Female participant, aged 31-35). Interestingly, the phrases used by participants in their comments are identical or very similar to the sentiments expressed in Study One (and hence the PCQ items). The degree of similarity suggests that the PCQ has strong face validity, and accurately captures the emotions experienced during this time. In addition to the emotional reactions during the illness, participants also noted the long-term emotional impact, noting the difficulties that they experience around the anniversary of their parent’s diagnosis and death, the sadness they experience when their parent is absent from special events (e.g., weddings, birth of children), and the guilt they experience when they have good times without their parent.

For the caregiver strain subscale the most strongly endorsed items were:

- I had to change my plans (e.g., vacations, work, study) as a result of my parent’s cancer;

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20 See Section 9.1 for a description and discussion of the benefit finding subscale.
21 While these two participants share the same gender and age category, the quotes are taken from two different participants.
I found it hard to juggle my obligations during my parent’s illness (e.g., work, caregiving, family, leisure), and I felt troubled by a great sense of responsibility for my parent during their illness.

Caregiver strain is mentioned in 14 qualitative comments, highlighting issues such as balancing work and care demands, the stress associated with caring, exhaustion, and the impact of caring on other family relationships. While many participants noted the strain associated with caregiving, three participants acknowledged the satisfactions arising from this role.

The frequency with which emotional aspects are mentioned reinforces the inclusion of the emotional experiences subscale in the PCQ, and positions the scale as a useful measure of both the positive and negative aspects of the experience of parental cancer. The inclusion of the caregiver strain items increases our understanding of issues surrounding involvement in care, and increases our insight into one potentially negative aspect of this experience. Importantly, the combination of positive and negative aspects in a single measure fits with Park’s (2004) assertion that, to gain a comprehensive insight into posttraumatic growth, we must examine both the positive and negative changes that arise from the stressful event. The PCQ examines both the benefits and negative changes, such as grief and loss issues, along with practical changes that arise due to involvement in caring for a sick parent. As such, the PCQ is unique in the field, and may assist clinicians in gaining a comprehensive assessment of issues arising from parental cancer in a single, relatively short measure.

It is interesting to note that the structure of the PCQ fits well with the pattern of findings that emerged from Study One. Specifically, the general conclusion of Study One was that benefit finding was a possible outcome of parental cancer. However, a greater number of benefits tended to be reported, if the participant had a strong emotional reaction to the situation and/or was involved in caregiving. In Study Two, correlation analyses investigating these relationships revealed significant positive
correlations between all subscales of the PCQ. This suggests that the level of benefit increases as the intensity of emotional reaction increases, and also as caregiver strain increases. It may seem counter-intuitive for a positive relationship to exist between caregiver strain and benefit finding. However, if caregiver strain is conceptualised as an indicator of involvement in caregiving, with higher strain potentially indicating higher involvement, then the positive correlation between these two subscales fits the pattern of results from Study One. Furthermore, it may be argued that caregiver strain may increase the perceived stressfulness of the parental cancer experience (e.g., witnessing parent suffering first hand, competing demands of various roles, facing own mortality). The increased perceived stressfulness contributes to an increased likelihood of a shattering of core beliefs, thereby increasing the likelihood that posttraumatic growth will develop and benefits will emerge (Janoff-Bulman, 1989, 1992; Tedeschi & Calhoun, 2004).

Preliminary evidence of the PCQ’s convergent and discriminant validity was also established in Study Two. Moderate to strong significant correlations were obtained between the PCQ’s subscales and other key measures that examine related constructs. Specifically, a moderately strong correlation was found between the PCQ benefit subscale and the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996), the emotional experiences subscale and the Reaction to Diagnosis of Cancer – Distress Scale (Frank-Stromborg, 1989) and the Grief Diagnostic Instrument (Clark et al., 2005-06), and the caregiver strain subscale and the Carers Assessment of Difficulties Scale (Nolan et al., 1998). It is, however, noted that the central aim of this thesis was not to establish a psychometrically advanced scale; rather the development of the PCQ occurred, when an alternate, pre-existing, suitable measure was unable to be found (see Appendix G for an examination of the scales reviewed prior to PCQ construction). Therefore, while the present study goes some way to establishing the psychometric properties of the PCQ, further investigation and possible refinement of the PCQ is warranted.
There are several key issues that are important in the continued development of the PCQ. While the initial assessment of reliability was excellent, no data was collected in relation to test-retest reliability, which will need to be addressed, if the PCQ is to be used as a measure to assess change at various points throughout the parental cancer experience. Furthermore, there is a need to establish normative data for the PCQ, and to determine if scores on the PCQ are influenced by demographic (e.g., gender, age) or illness variables (e.g., type of cancer, outcome of parental cancer, gender of parent). This will require the use of the PCQ in a large scale study to ensure that adequate representation of targeted groups (e.g., children of parents with melanoma, bereaved individuals) is obtained. This is especially important, as there is some suggestion that gender may influence the type of benefits derived from stressful experiences (see Section 9.1). Furthermore, several studies (e.g., Oktay, 2005; Thornton & Perez, 2006; Weiss, 2004) have suggested that illness variables may influence benefit finding. Therefore, these potential relationships need to be investigated to establish normative data, before the PCQ can claim to be a superior measure.

The initial validity information regarding the benefit subscale of the PCQ was obtained through correlation with the Posttraumatic Growth Inventory (PTGI, Tedeschi & Calhoun, 1996). While the PTGI is a well-validated and standardised measure, and has been used as a measure of benefit finding in other research (Helgeson et al., 2006), it is acknowledged that the PTGI is primarily a measure of posttraumatic growth, a theoretically related concept. It is therefore recommended that future validation studies include a specific benefit finding measure such as the Benefit Finding Scale (Antoni et al., 2001; Tomich & Helgeson, 2004) or the Perceived Benefits Scale (McMillen & Fisher, 1998).

Another issue relating to the PCQ’s validity is the possibility that the PCQ benefit subscale may actually measure social desirability, since the benefits contained in the items represent highly desirable outcomes. However, a study by S. G. Smith and Cook (2004) found that individuals, who were asked to rate benefit finding linked to a specific event (as was the case in Study Two), reported lower levels of growth compared to
individuals who completed the growth measure that was unrelated to an event. S. G. Smith and Cook (2004) suggest that linking the growth scale to an event may prompt individuals to be overly cautious about attributing growth to the event, probably due to cognitive dissonance surrounding the notion of finding something good in a bad situation. Additionally, Tedeschi, Calhoun, and Cann (2007) argue strongly against the assertion that self-reported growth reflects self-enhancing cognitive biases and social desirability. Tedeschi et al. cite research that has found no correlation between growth and social desirability measures, and that self-reported growth has been corroborated by others (e.g., Weiss, 2004). To clarify this issue in relation to the PCQ, future studies, aimed at establishing the PCQ’s psychometric properties, should include a measure of social desirability, such as the Marlowe-Crowne Social Desirability Scale (Crowne & Marlow, 1960). Additionally, the use of corroborating reports of growth from other family members, spouses and close friends, as suggested by several researchers (e.g., Park, 2009; S. G. Smith & Cook, 2004; Stanton & Low, 2004), may provide further evidence of the degree of positive change. Such improvements to study design would enhance our understanding of the validity of the PCQ.

The discriminant validity of the PCQ would also be further established, if relationships could be demonstrated between the PCQ and other variables known to be related to benefit finding. Variables to consider including in future psychometric studies are optimism and hardiness (Zoellner & Maercker, 2006), social support (Linley & Joseph, 2004; Prati & Pietrantoni, 2009), positive affect (Stanton & Low, 2004), and coping (McMillen, 2004).

Despite the promise demonstrated by the PCQ, there remain several limitations to self-reported growth measures that the PCQ does not address. For example, a very high proportion (95%) of the sample reported the presence of at least one benefit, demonstrating the concern expressed by Nolen-Hoeksema and Davis (2004), that the ‘checklist’ style of data collection may over-inflate actual positive change. Additionally, the PCQ is unable to address the concerns raised by Coyne and Tennen (2010), that
9.5 Research Limitations and Implications

As with much self-report, cross-sectional survey research, there are a multitude of issues surrounding the accuracy of the data collected. In addition to the limitations noted in Section 9.4 in relation to the PCQ, the following limitations are identified. Particularly relevant to the current study is the accuracy of recall of events, as there was no time limit set regarding how long ago the participant’s parent had been diagnosed with cancer. While longitudinal studies (e.g., Carver & Antoni, 2004; Lelorain et al., 2010) do suggest that growth is a long-term phenomenon in cancer patients, it is presently unclear how time since diagnosis may influence the reported benefits in children of cancer patients. Furthermore, traumatic events, other than parental cancer, may have coloured participants perceptions of growth, and Study Two did not ask questions on this matter, so they were unable to be controlled for in analysis. Finally, Study Two did not contain a control group (i.e., adults whose parents did not have a diagnosis of a potentially fatal, chronic medical condition), and therefore there is no way to gauge whether the types of benefits reported in the current findings reflect changes that may simply have occurred over time.

The cross-sectional nature of the data has only allowed for the measurement of perceived benefit finding at one time and, as such, the potential to examine changes in benefit finding arising at various stages of the parental cancer experience has not been studied. This is a significant limitation, and prevents an examination of the theoretical distinction between growth as construction or growth as illusion, or the Janus Face model (Zoellner & Maercker, 2006). However, considering the scant research on the topic of benefit finding with this target cohort, it seemed prudent to start simply and confirm that perceived benefit finding was an outcome in this group. Now that this hypothesis has been confirmed, future
studies can be designed to address the methodological flaws outlined above, and it is recommended that such studies employ a longitudinal design, following individuals over a minimum 12 month period from the time of diagnosis, gathering information relating to benefit finding and posttraumatic growth from multiple sources, with the inclusion of a control group.

In addition to the general limitations noted above, there are additional limitations surrounding two measures and the data collection technique. Specifically, the Reaction to Diagnosis of Cancer Questionnaire (RDCQ) has only been used in studies of cancer patients, and therefore its suitability of use in a sample of non-patients was questionable. Nolan, et al. (1998) argue that the Carer Assessment of Satisfactions Index should not be used as a summed scale to measure overall satisfaction, but rather used as a tool to identify areas of strength in the caregiving situation. While this may be a suitable use for the measure in a clinical setting, it is not practical in a research environment, and therefore a total score was obtained. The reliability data for those two scales in the current study, however, indicates that the measures meet the standard of reliability required for research, with both measures reporting internal consistency in excess of .80 (Garson, 2010). Furthermore, the RDCQ was not used in any critical analysis related to benefit finding (it has been used to help establish preliminary validity of the PCQ), and therefore any issues relating to the use of this measure may be considered minor. The finding that carer satisfaction was a predictor of benefit finding is more problematic, and it is therefore recommended that this result be interpreted cautiously, until it is confirmed by other research.

In relation to the data collection technique, there are many advantages of on-line surveys, including the ability to recruit a large sample (and thereby increasing power), time efficiency, flexibility, ease of circulation and increased access to specialised sample groups such as individuals with rare conditions (Birnbaum, 2004). However, there are potential disadvantages to this methodology, namely self-selection, representativeness, uncontrolled circulation, multiple submissions, higher drop out rates, and the unknown setting in which participants complete the
survey (Birnbaum, 2004; Stieger & Reips, 2010). Additionally, a range of participant behaviours conducted, while completing the survey (e.g., clicking through sections, excessive clicking, changing answers, and periods of inactivity suggesting distractibility), may influence the internal validity of the data. The current study did not employ technological tools that can be used to collect additional behavioural data (known as paradata) to assist in the judgement of data quality. Future studies, which wish to consider this aspect of data quality, should collect data using script language that are part of standard web browsers, or use tools such as UserActionTracer (Stieger & Reips, 2010). A final limitation of the survey utilised in Study Two relates to its length and that the order of measures was not randomised. These two factors may contribute to issues regarding data quality, particularly in relation to order and fatigue effects.

The Parental Cancer Questionnaire (PCQ) can be conceived as both a strength and a limitation of the study. The combination of positive and negative aspects of the parental cancer experience in a single measure is an important development for research in this area. Park (2004) argues that true insight into posttraumatic growth will only be accomplished through the examination of positive and negative aspects of the experience, and the PCQ accomplishes that. Furthermore, the items have been data driven in their development, and therefore reflect the lived experience of individuals who face the stresses associated with having a parent with cancer. The reliability of the scale is very good, and the emerging validity data is encouraging. Consequently, it is suggested that the PCQ is a strong measure that is suitable for use in both research and clinical environments. The measure will, however, be improved with continued psychometric development, and this type of research is strongly encouraged.

Despite these positive aspects of the PCQ, there are some concerns raised by existing research. Specifically, Kim and colleagues (2007) found that different domains of benefit finding related differently to the reported level of depression. In that study, benefit finding in the domains of acceptance and self-view contributed to lower levels of depression, while empathy and reprioritisation were found to increase depression (Kim et al.,
This finding by Kim et al. argues for the use of a benefit finding measure, which contains several benefit subscales, to fully understand how benefit finding contributes to mental health outcomes arising from stressful events. There is also some discrepancy between the current findings and existing research, regarding the type of perceived benefits most likely to arise from having a parent with cancer. The current study suggests that family-related benefits are most likely, while spousal research (e.g., Manne et al., 2004; Wong et al., 2009) suggests that personal strength and new possibilities as the strongest areas of growth. As such, the use of a benefit finding measure with multiple domains is required to assure that adequate information is obtained for comparison.

The problem for the PCQ lies in the finding of the current principal components analysis, which suggests that the PCQ contains only one perceived benefit subscale. Although originally written with four benefit sub-scales mirroring the themes of Study One, the analysis of the full PCQ was unable to find more than one coherent benefit subscale. The additional analysis of the benefit only items did find four components. However, the components contained only two or three items and, as such, were grossly limited in the information that they could provide into the benefit finding phenomenon. Consequently, it was concluded that the PCQ is best conceptualised as a measure with one perceived benefit subscale. However, future research with larger sample sizes may find a different component structure with multiple benefit subscales that will add depth to the PCQ. It is therefore recommended that the next stage of development for the PCQ should involve the full 53 item scale, until the component structure is confirmed or refined.

While the finding of perceived benefits in the current study goes some way to supporting the basic premise of posttraumatic growth theory, it is unable to determine whether actual posttraumatic growth occurred, and if so, through which means such growth arises. This is due to the omission of measures that examine the cognitive processes and coping responses, which people undergo when they face parental cancer. Such measures were excluded at this point in time, as the study aimed to confirm whether
perceived benefit finding would emerge in this cohort, and then to gather some additional information surrounding the predictors of perceived benefit finding and its relationship with psychological outcomes. Furthermore, the inclusion of the PCQ, an untried and invalidated measure due to the lack of a suitable alternative, meant that scales needed to be included that would help to demonstrate the psychometric properties of the PCQ. As such, the survey instrument used for the study was already long, and concerns were evident regarding participant recruitment and drop-out during survey completion. Consequently, the decision was made to omit a cognitive process and coping measure to avoid problems with recruitment and missing data, due to participants’ failure to complete the survey. Future research, which looks to replicate and extend the current study, would do well to include such measures. Furthermore, it is noted that two new measures, the Core Beliefs Inventory (Cann et al., 2010), and the Event Related Rumination Inventory (Cann et al., 2011) would be an ideal inclusion to future studies. These new measures would allow researchers to assess the cognitive changes and processes that individuals experience to accommodate the stress arising from parental cancer.

It is also important to stress that research into the area of posttraumatic growth and benefit finding in the adult children of cancer patients is in its infancy. As such, there is much that needs to be investigated beyond the variables examined in the current thesis. Indeed, it may be suggested that parental cancer can be viewed as both a family and personal crisis, and therefore a range of personal and relational variables may influence the level and types of benefits that emerge. For example, existing research suggests that optimism (Prati & Pietrantoni, 2009) and hardiness (Zoellner & Maercker, 2006) are related to posttraumatic growth outcomes, and future studies investigating such variables may reveal whether these traits are significant in the development of growth and benefits for this cohort. Furthermore, studies that examine family related variables such as family cohesion, communication and conflict (as measured through tools such as the Family Relationship Index [Moos & Moos, 1986] and the McMaster Family Environment Scale [Epstein, Bishop, Ryan, Miller & Keitner, 1993]), the division of care responsibilities within family networks,
and obtain data from multiple family members may all be worthy areas of investigation.

In terms of clinical implications, the author highlights Coyne and Tennen’s (2010) concern that, at present, there is too much uncertainty in the field of benefit finding to warrant a strong push to integrate such concepts into clinical interventions. Coyne and Tennen argue that we do not understand “the circumstances in which finding benefit has positive adaptational value” (p. 19). Such a warning implies that there may be situations in which a push towards benefit finding may actually do harm, or be inappropriate as a therapeutic tool.

In the light of this warning, the following comments are suggested for those who wish to gain an understanding of the potential clinical utility of these findings. The main clinical finding is that higher perceived benefit finding is linked to lower levels of depression and, as such, may act as a protective factor that either (a) reduces the likelihood of developing depression, or (b) reduces the severity of depression. Previous research has demonstrated that interventions, which involve the development of coping skills associated with benefit finding, may be one such avenue for intervention. Specifically, Sears et al. (2003) argue that the simple presence of benefit finding is unrelated to positive affect, rather the use of benefit finding as part of positive reappraisal coping contributes to both physical and mental well-being. Antoni et al. (2001) also report on the success of a 10 week cognitive behavioural stress management intervention for breast cancer patients, finding that the intervention increased the level of benefit finding, reduced depression and enhanced optimism. This intervention focused on various aspects of coping with cancer, including optimising the use of social support, increasing emotional expression, cognitive restructuring, conflict resolution and coping with daily and treatment-related stressors. Calhoun, Tedeschi, Cann, and Hanks (2010) suggest that individuals, who engage in rumination as a coping mechanism, can have that rumination transformed from being intrusive and unconstructive to being deliberate and focused onto questions, which may give rise to the development of posttraumatic growth. It is, therefore, suggested that
strategies, which enhance positive cognitively-based coping approaches, may have some merit for inclusion in interventions. However, interventions aimed entirely at eliciting benefit finding should be avoided.

The timing of benefit linked interventions may also be important, and it is suggested that growth may play a different role at various times in the grieving process. Sawyer et al. (2010) suggest that post-traumatic growth may be a useful target in the early stages of grief to reduce distress, but that, to have an impact on longer-term well-being, posttraumatic growth should be targeted in the later stages of adjustment. Calhoun et al. (2010) further stress the importance of timing, suggesting that the psychologist must be “sensitive to the readiness of people to consider emerging indications of growth” (p. 137), rather than engaging with the individual from the assumption that growth will arise and that growth is good.

Despite the positive findings and the cautions about timing, there remain concerns regarding the suitability of using benefit finding in interventions. The suggestion that the individual can, or should, try to find benefit in a negative experience may be seen by some as offensive, and may interfere with the grief process. To avoid this, Calhoun et al. (2010) suggest that the psychologist should adopt the role of an expert companion, a support who stays with the individual through the grief process, regardless of the duration of grief, who is willing to hear and respect the individual’s beliefs, and who highlights growth when it emerges. It is, however, stressed that the growth should be attributed to the individual’s struggle with their loss, not the loss itself, to avoid the potential for cognitive dissonance arising from the conclusion that the loss is good per se.

Finally, it is again stressed that several authors (e.g., Coyne & Tennen, 2010; Lechner, Tennen, & Affleck, 2009; Sawyer et al., 2010) have expressed concern about the suitability of interventions focusing on benefit finding. For example, Sawyer et al. (2010) concluded, in their review, that large scale interventions targeted at enhancing posttraumatic growth should, at this time, be avoided. This is due to the relative disagreement and ambiguity within the field, and therefore Sawyer et al argue that large
Interventions should wait, until there is a greater understanding about the origins of posttraumatic growth, its measurement, and its relations to psychological health. Lechner et al. (2009) express similar sentiments when they state “In view of the clearly mixed findings linking [benefit finding] and positive adaptation, we urge clinicians to respect [benefit finding] when emerging spontaneously, while constraining their enthusiasm for inducing [it] among clients” (p. 638).

In summary, this chapter has reviewed the key findings of Study Two, demonstrating consistencies with the existing theoretical and empirical literature, and highlighting areas for future research. Specifically, the chapter began with a review of the types of perceived benefits reported by adults whose parents have cancer, noting that the main area of benefit appears to be in relation to family. This finding was contrasted to spousal studies, and there is some suggestion that gender may influence the types of benefits reported. The predictors of perceived benefit finding were discussed, with particular attention to the possible moderating effect of outcome of parental cancer on the relationship between emotional experiences and benefit finding. The finding that perceived benefit finding predicts depression was discussed, and it is suggested that benefit finding may act as a protective factor which prevents the development of depression, or reduces symptom severity. The null relationship between perceived benefit finding and well-being was discussed in relation to theoretical context and possible measurement issues. The development of the PCQ was also reviewed, with the strengths and limitations of the scale being identified. It is strongly recommended that additional research be conducted to refine the PCQ, as it has great potential research and clinical utility. The limitations of the study relating to design, measurement, and data collection strategy were discussed. Finally, the clinical implications were highlighted, albeit with the cautionary warning that our current understanding of benefit finding may indicate that clinical interventions at this time may be premature.
Chapter 10: Summary of Findings and Implications for Future Research and Clinical Practice

This thesis has investigated the concept of benefit finding among adults whose parents have cancer. Specifically, it has aimed to confirm that benefit finding exists within this cohort, expand the knowledge regarding the types of benefits experienced, while also examining the predictors of benefit finding. Finally, the thesis aimed to examine the relationship between benefit finding and the psychological outcomes of depression, anxiety and well-being. As the research aims were examined over two studies, this chapter presents a summary of the key findings, from both studies, highlighting the importance of such findings and briefly discussing them in the light of existing knowledge (more detailed discussions are included in the Chapters 5 and 9). This chapter emphasises potential avenues for future research that the thesis raises, while also discussing the implications of the findings for clinical practice.

10.1 Summary of the Research

The concept of benefit finding arising from cancer has been increasingly studied over the last 20 years, primarily in cancer patients themselves, and to a lesser degree among the spouses and young children/adolescents of cancer patients. In examining the benefit finding literature, a clear void was identified in that very little was known about whether the adult children of cancer patients reported similar positive outcomes. This was perceived as a significant oversight in the current status of knowledge on this topic, as most children of cancer patients will be adults as cancer is a disease that typically occurs later in life.

A review of the cancer-related literature highlighted only two quantitative studies, which had examined the concept of benefit finding in adults whose parents have cancer, and both studies contained significant flaws. Firstly, the study by Mosher et al. (2006) found that posttraumatic growth was present in a cohort of daughters of breast cancer patients. However, their sample size was small by quantitative standards, and the researchers did not detail the types of benefits reported, instead only
reporting total posttraumatic growth scores. The second study by Leedham and Meyerowitz (1999) again suggested benefit finding to be an outcome. However, participation in that study required that the experience of parental cancer occurred during childhood or adolescence and, as such, did not assess whether having a parent with cancer during adulthood could lead to the development of psychosocial benefits. A detailed examination of a variety of qualitative studies into the general experience of parental cancer did provide some insight into the topic, with the presented data suggesting that adult children could indeed derive benefits from their parent’s cancer, across multiple domains. In the light of this literature review, it was determined that the concept of benefit finding in parental cancer was a valuable area of study, that had been largely unresearched in the past.

The concept of benefit finding stems from theoretical works in the area of posttraumatic growth. Theories in this field identify that individuals can potentially develop a range of outcomes in response to trauma, with positive change and growth a frequent by-product of traumatic experiences. There is debate within the field as to whether posttraumatic growth is best conceptualised as an outcome (Janoff-Bulman, 1989; Tedeschi & Calhoun, 1995) or a coping process (Taylor, 1983), with empirically supported theories proposed that validate both arguments. Recent developments have seen the proposal of the Janus Face model (Maercker & Zoellner, 2004), a theory that suggests that posttraumatic growth is both an outcome and a coping process, with each type of growth emerging at different times in the trauma response. While the present thesis did not attempt to examine a specific theoretical position in the target cohort, the data that was obtained in Study One and Two have been reviewed and, where possible, linkages to theoretical models were highlighted.

A qualitative study \( (n = 11) \) was conducted for Study One, which confirmed that the adult children of cancer patients did perceive benefit finding to arise from their experience with parental cancer. Additional information regarding the types of benefits that arose from this experience was also gathered in this study. The data was examined in the light of the key theories of posttraumatic growth to identify if any such theories
demonstrated relevance to this cohort (See Section 10.2 for a summary of the main findings).

A clear pattern emerged from the data of Study One, namely that perceived benefits do arise. However, participants seemed to report more benefits if they described their parent’s cancer as having a high emotional impact, and/or if they were involved in their parent’s caregiving. This pattern of findings shaped the second quantitative study, which aimed to confirm whether such a relationship existed in a larger sample. In preparing for Study Two, a research need was identified; essentially there was no existing scale that measured the emotional impact of parental cancer on adult children. To address this need, the data from Study One was used to construct a measure, the PCQ, which examined not only the emotional experiences of this group, but also contained items relating to the types of benefits reported to arise out of parental cancer, as well as items relating to involvement in caregiving (i.e., the pattern of findings from Study One was reflected in the content of the PCQ). In its original form, the PCQ was a 53 item scale, with seven subscales, four describing cancer-related benefits, and three examining more negative experiential and affective aspects of parental cancer.

Study Two extended the findings of Study One, confirming that perceived benefit finding does occur in response to parental cancer, while also providing confirmation of the types of perceived benefits reported by the target cohort. The PCQ was analysed using principal components analysis, with the findings suggesting a three component scale, rather than the seven components indicated from the themes emerging from Study One. The pattern of findings from Study One, that benefit finding was higher in participants reporting higher emotional experiences and involvement in caregiving was partially supported in Study Two, with perceived benefit finding being predicted by emotional experiences, caregiver satisfactions and the outcome of parental cancer. Finally, the predictive utility of benefit finding in relation to depression, anxiety and well-being was examined, with the results suggesting that perceived benefit finding may serve as a protective factor against depression, but is unrelated to anxiety and well-
being (see Section 10.3 for a more detailed summary of the main findings of Study Two).

The following sections provide further detailed examination of the key findings from both Study One and Study Two, highlighting the understanding that these studies contribute to the area of benefit finding research and theory by identifying new findings, and emphasising those that confirm previous research.

10.2 Summary of Main Findings from Study One

There are four important findings to emerge from Study One, namely:
1. Perceived benefit finding does occur in response to parental cancer, across multiple domains.
2. The experience of parental cancer is highly stressful and emotional, and this should not be overlooked, simply because participants also derived benefits from the experience.
3. Benefit finding appears to be related to the emotional intensity of the experience and/or involvement in caregiving.
4. There is evidence to suggest that benefit finding may be both an outcome and a coping process, and as such there is tentative support for the theoretical position argued by the Janus Face model of posttraumatic growth.

10.2.1 Main finding one: Types of perceived benefits emerging from parental cancer.

The data from the 11 semi-structured interviews was analysed, using an interpretative phenomenological analysis, aimed at gaining an insight into the types of benefits arising from parental cancer as they are perceived by the individual, and the meaning that may be assigned such benefits. Emerging from the data were four clear benefit-related themes, demonstrating that benefit finding is possible from parental cancer, and that it occurs across multiple domains.
The first theme to emerge was *transforming the relationship with the sick parent*, which was evidenced by participant reports of perceived positive developments or changes in their relationship with their parent with cancer. The types of positive changes included an enhanced sense of closeness, learning more about each other, spending more leisure time together, improved communication, and resolving old conflicts. There was also a growing respect and appreciation for the sick parent, recognising the valuable role that they play in the family system, and an admiration for the behaviours they displayed throughout their illness.

The second theme was *family matters*, which reflected the participants’ acknowledgement of positive change in their relationships with other family members, and an enhanced sense of valuing family. Case examples were presented of participants reporting the perception of improved relationships with their healthy parent, siblings, and extended family members, usually demonstrated through increased contact, enhanced communication, and reciprocal support. Importantly, there are negative case examples in this theme, with some participants also reporting a decline in their family relationships. Such declines were usually related to how the adult child perceived the family member was relating to the sick parent, or inequities related to caregiving. Many participants also reported an enhanced sense of the value that family has in their lives, recognising it as a priority, and that the family requires time and effort rather than neglect.

The third theme was *altered life priorities*, which reflected perceived positive changes in attitude relating to outlook on life, core values, or life philosophy. The main areas of changed outlook related to valuing relationships, an altered perception of the importance of work, an enhanced sense of adventure, and a more philosophical outlook on life represented by the sentiment of making the most of each day. Importantly, such changes in outlook were often reported to be accompanied by behavioural changes, such as job changes, reduced work intensity, increased travel, and a greater balance between work and family commitments. There was also the sense that participants perceived that their experience with parental cancer had provided participants with an opportunity to reassess their attitude towards
key areas of their life, and redefine their priorities and how they chose to interpret situations.

The final theme was personal development, which represented perceptions of change relating to personal qualities, self-view, and health behaviours. Participants reflected on changes relating to their compassion for others, increased wisdom and emotional maturity, as well as an enhanced sense of independence. Some participants recounted that they had become more confident and assertive; however, these changes were usually in relation to asserting oneself towards medical professionals. Some participants also discussed beneficial changes in their health behaviours, with such behaviours targeted at reducing the personal risk of cancer and/or early detection of the disease.

The significance of these themes should not be underestimated, as they essentially answer the central question of this thesis: is it possible to derive benefits from having a parent with cancer? The four themes answer that question affirmatively, not only is it possible to derive benefits, it is possible to derive multiple benefits across multiple aspects of life. Importantly, the types of benefits, which are reported by the participants in Study One, are very similar to the types of benefits that are reported in the research into cancer patients and spouses. For example, Hilton et al. (2000) described how cancer couples created special time together in an effort to enhance their relationship. Comparable sentiments are expressed in Study One by several participants, as one participant reported increased participation in leisure activities with his father, and other participants described how they got closer to their ill mothers. In another example, Germino et al. (1995) and Gray et al. (2000) concluded that spouses often reassessed their commitment to work during the cancer experience, while, in Study One, three participants reported considerable changes to the importance they placed on work in an effort to accomplish a better work-life balance.

The similarity between the themes in Study One and the findings of other researchers raises the question as to whether the classifications of
beneficial outcomes proposed by theorists Tedeschi and Calhoun (1995) and cancer researcher Thornton (2002) are relevant to the adult child cohort. Both Tedeschi and Calhoun and Thornton proposed that growth occurs in the areas of self-perception, interpersonal relationships and life perspective. It is quite evident that the themes emerging from the data in Study One fit well within those classification systems. Specifically, evidence of interpersonal benefits is present in the themes of *transforming the relationship with the sick parent* and *family matters*, while *personal development* matches the category of growth associated with self-perception. The theme of *altered life priorities* fits primarily within the category of growth relating to life perspective, however the sub-theme of valuing people and relationships is best conceptualised as falling within the growth category of interpersonal relationships. This finding of great similarity between the themes reported in Study One and the pre-existing theoretical categories of themes confirmed the second aim of Study One.

While there is certainly similarity in the broad classifications of themes, there were some notable differences in the types of perceived benefits reported as personal development in Study One compared to other findings. For example, Thornton (2002) cites studies of cancer patients that found increased self-worth, taking more time for self, improved self-image and increased satisfaction with life accomplishments, however, such themes not represented in the data from the participants in Study One. Oktay’s (2005) study, involving daughters of breast cancer patients, found evidence of increased self-worth and taking time for self, themes that are not present in this study.

One area of commonality is reported changes in health behaviours aimed at reducing the personal risk of cancer and/or early detection of the disease, if it does develop. Oktay (2005) presented data of participants consciously choosing healthier lifestyle options, such as exercise, stress reduction and dietary changes. While there is some evidence of health behaviour change in Study One, the main focus was on medical testing to detect cancer, rather than on lifestyle behaviours that may help to prevent the disease. The health behaviour changes in the present study are more
consistent with the Tarkan (1999) data, with Tarkan presenting two cases discussing increased medical testing for cancer detection and zero cases mentioning lifestyle factors. However, the Tarkan data relates to genetic screening, and this was not mentioned by any of the participants in the current study. Such discrepancies between the studies may reflect real differences between the populations, or may be related to methodology and the type of questions asked during the interviews.

Another potentially significant finding is that the theme of personal development was substantially less prevalent (i.e., mentioned less frequently, discussed in less detail) in the data from Study One in comparison to the other themes. Possible explanations for this finding include reduced introspection, as attention is directed externally to the patient, increased workload and role strain, which limits time for self-development activities, or methodological limitations. Taken together, the findings of different types of personal development benefits, and the reduced emphasis on personal development within the current sample, indicate that this is an area requiring further research.

10.2.2 Main finding two: Parental cancer is a highly emotional and stressful time.

Despite the finding that adult children do derive benefits from their experience of parental cancer, the data obtained in Study One strongly indicated that this was a very stressful and emotional time in the participant’s life. The three negative experience themes provide evidence of the struggle that adult children grapple with during their parental cancer experience. The theme of experience intensity reflects the emotional and cognitive reactions to their parent’s diagnosis, and the longer term impact as the disease progressed. The accounts, which were shared by participants, indicated that many of them underwent an intense emotional struggle, with some participants reporting their parent’s cancer as the most significant event in their lives. Participants reported a strong need to be close to their parents, and the language used by some participants indicated quite a deep enmeshment in their parent’s lives. A range of emotional experiences were
also reported, including guilt, shock, uncertainty, anger, frustration, and isolation.

The grief and loss theme examined both the immediate losses that arise when one’s parent is diagnosed with cancer, but also the long-term grieving that occurs, regardless of whether the parent survived their disease. The participants reported a sense of a shattering of their sense of security, as their primary attachment bond was threatened by the disease. Loss was also experienced through declines in other key relationships, changes in the sick parent, so they were noticeably different to their pre-cancer self, and a sense of unresolved grief and lingering sadness. For some participants, bearing witness to their parent’s suffering was recounted as an extremely difficult experience that still troubled them. Importantly, there are negative case examples present in the data that suggest that, for some adult children, being present at the end of their parent’s life (i.e., at the time of death) was important for their adjustment, in the sense of being able to say goodbye and support their parent at that critical time.

The final negative experience theme of involvement in caring was defined as actual and perceived changes in role and circumstances, arising from the provision of support to and contact with a parent with cancer. A key element of this theme was changes in role for the adult child, often taking on more responsibility for various aspects of their parent’s life and care. Such changes involved attending medical appointments, involvement in treatment-related decision making, managing finances, assisting with activities of daily living, and communicating with other family members about the parent’s condition. For some participants, this involvement in care gave them a sense of control, while others felt a strong sense of duty to assist their parents. The concepts of protecting the parent, and role reversal (i.e., parenting the parent) were also present. A final dimension to this theme was that such role changes often gave rise to problems in other dimensions of the adult child’s life, usually in their relationships with other family members.
Many of the fundamental sentiments expressed in the negative themes are echoed in existing research. For example, Mellon’s (2002) study found that family members can feel devastated by a cancer diagnosis, and Harrison et al. (1995) found elevated levels of distress in family members. Previous research has suggested that strong emotional reactivity in family members may be due to conflict within the family (Kissane et al., 1994) and inadequate social support (Pitceathly & Maguire, 2003), both of which are present in the data from Study One. Conflict related to caregiving has also been reported extensively, both in terms of conflict between siblings (e.g., Strawbridge and Wallhagen, 1991) and with the caregiving child’s spouse (e.g., Bookwala, 2009).

The emergence of the negative experiential themes is very significant, as it provides a context within which the other data can be interpreted. As such, these themes enhance the interpretative phenomenological analysis approach by assisting the researcher to get a true understanding of what the experience of parental cancer was like from the participant’s point of view. By providing evidence of negative aspects of the experience, the possibility of gaining greater insight into the growth phenomena is enhanced, as Park (2004) argues that, to fully comprehend how growth contributes to adjustment, we must examine both positive and negative aspects of the trauma. The themes provide support for the contention that parental cancer would be defined as a traumatic experience under the broad definition of trauma proposed by Tedeschi and Calhoun (1999). Furthermore, the negative experiential themes are also supportive of the theoretical arguments of Janoff-Bulman (1992) and Tedeschi and Calhoun (2004) that growth arises from the individual’s struggle with their trauma.

10.2.3 Main finding three: Relationship between perceived benefit finding, emotional reactions, and involvement in care.

An interesting finding to emerge from Study One was that participants, who reported a high degree of emotional reaction (as gauged through the experience intensity and grief and loss themes) and/or involvement in their parent’s care, also tended to report a higher number of
perceived benefits. This finding mirrors the fundamental premises of posttraumatic growth theories that the event must be traumatic enough to challenge core beliefs, and that growth arises from the individual’s struggle with their trauma (Janoff-Bulman, 1992; Tedeschi & Calhoun, 2004). Indeed, it is proposed that the process of struggle, which gives rise to the creation of new, more realistic schemas through the creation of meaning in the traumatic event, is the basic process that gives rise to growth in the form of benefit finding. The pattern to emerge in the data from Study One seems to indicate that higher levels of emotional reactivity (which may be an indication of higher levels of trauma) may lead to the shattering of assumptions and prolonged periods of struggle, and therefore does bring forth higher levels of benefit finding.

The pattern of findings also suggested that the adult child’s involvement in caring for their sick parent may contribute to the level of benefits reported. It is suggested that this may occur due to two reasons: firstly, the role changes associated with caring for the sick parent increase the emotional intensity of the experience, as such changes are often perceived as stressful. Secondly, involvement in care brings the adult child face to face with their parent’s suffering and vulnerability, therefore increasing their contact with the traumatic event. Through these two mechanisms, the likelihood for traumatisation is increased, and so opportunities for growth are more likely. It was this pattern of finding of a potential relationship between these key variables that inspired the second study for this thesis.

10.2.4 Main finding four: Utility of the Janus Face model of posttraumatic growth.

The third aim of Study One was to examine the data to determine whether it supported a theoretical position on posttraumatic growth. The data suggests that there is evidence of growth as both an outcome (as proposed by theories such as Tedeschi and Calhoun, 1995, 2004, and Janoff-Bulman, 1992) and an illusory coping process (as proposed by Taylor, 1983). There are case examples of benefit finding as an outcome of the parental cancer experience, with some participants reporting changes in
their interaction patterns with their sick parent, altered outlook on life, and changes to their health behaviours. Case examples that support the notion of benefit finding as an illusion include situations where participants describe how involvement in caregiving gave them a sense of control. However, the strongest evidence of growth as an illusion was presented in the case of Cathy, whose comparison of her father pre and post cancer had helped her deal with the crisis of losing him. However, she was now struggling to reconcile the two versions of her father that she had created.

The presence of examples of both forms of posttraumatic growth (i.e., outcome and illusion) suggests that potentially both theoretical models have some applicability within the adult child cohort. There is also the suggestion that both models are dominant at different times during the parental cancer experience. The illusory coping mechanisms of control and social comparison were described as present during the acute traumatic stages (i.e., treatment and bereavement), but not present in cases detailing longer-term adjustment. In contrast, many of the outcome-based benefits were evident long after the acute trauma stages. As such, there is tentative support for the applicability of the Janus Face model of posttraumatic growth proposed by Maercker & Zoellner (2004; Zoellner & Maercker, 2006). However, future studies are warranted before firm conclusions can be drawn.

10.3 Summary of Main Findings from Study Two

In addition to the four main findings emerging from Study One, there are four important findings to emerge from Study Two, namely:

5. Benefit finding was confirmed in a larger sample, with the most commonly reported benefits relating to family.
6. Emotional experiences, caregiver satisfaction, and outcome of parental cancer were predictive of benefit finding.
7. Benefit finding was predictive of depression, but not of anxiety and well-being.
8. The Parental Cancer Questionnaire is a suitable measure of the experience of parental cancer.

List numbering has continued from the previous list of findings from Study One.
10.3.1 Main finding five: Benefit finding is possible, particularly in the area of family.

Study Two confirmed that benefit finding does occur in adults whose parents have cancer, with 95 – 98% of the sample reporting at least one benefit. An examination of the types of benefits endorsed by the participants revealed that the most common area of benefits were associated with the relationship between the sick parent and adult child, and spending more time with family. This finding matches that of Study One, which found that benefits related to the sick parent and an increased emphasis on family were the most common benefits reported.

Study One suggested that personal development benefits were less likely in adults whose parents have cancer, as they were mentioned less frequently, and discussed in less detail to benefits in other areas. The principal components analysis on the Parental Cancer Questionnaire (PCQ) revealed that the personal development items consistently failed to load as a component, and in the final version of the PCQ, the only personal development item that was retained was related to spiritual development (which some may argue actually represents an altered outlook on life).

Taken together, the results from Study One and Study Two suggest that perceived benefit finding is most likely in the area of family, and least likely in the area of personal development. There is mixed support for this conclusion in previous studies of cancer patients and spouses. Several studies confirm that benefit finding in relation to family is a frequent outcome. For example, Dorval et al. (2005) found that the marital relationship was enhanced in breast cancer couples, and Gray et al. (2000) reported an increased sense of closeness and improved communication between cancer patients and their spouses. The qualitative studies with samples of adult children provide case examples in which improved family relationships are evident, including increased closeness and connection between the child and sick parent, improved communication, and efforts to spend more time with family (Baxandall & Reddy, 1993; Oktay, 2005; Tarkan, 1999).
However, there are also conflicting findings, which suggest that benefit finding is stronger in other domains. For example, Wong et al. (2009) identify personal strength as the strongest area of growth, followed by enhanced relationships between carer and patient, in a study of cancer caregivers. Similarly, Manne et al. (2004) found that their sample of breast cancer spouses reported greatest growth in the domains of personal strength and new possibilities for life. These findings are in sharp contrast to the conclusion drawn from the two studies in this thesis. This discrepancy may be due to the high proportion of female participants in the current study, issues regarding the types of personal development items on the PCQ, or alternatively, it may reflect a key point of difference for adult children compared to patients and spouses.

10.3.2 Main finding six: Benefit finding is predicted by emotional experiences, caregiver satisfaction, and outcome of parental cancer.

The second aim of Study Two was to examine variables that may be potential predictors of benefit finding. Hierarchical multiple regression analysis found that benefit finding was predicted by three variables: emotional experiences, caregiver satisfactions, and outcome of parental cancer. Specifically, higher levels of emotional reaction and higher carer satisfaction are associated with higher levels of benefits. In relation to emotional experiences and posttraumatic growth outcomes such as benefit finding, similar results have been found in both adult children (Mosher et al., 2006) and spousal studies (Weiss, 2004), with higher perceived stressfulness being associated with greater positive change. The result that benefit finding is predicted by carer satisfaction is a relatively new finding, with very little research being conducted in that area. The research, which has examined the two variables, together has found a positive relationship between the two (Foster et al., 2010; Walker et al., 1990). However, the prediction of benefit finding using the caregiver satisfaction variable has been untested.

It was also found that benefit finding is predicted by the outcome of parental cancer, however, it remains unclear exactly what the relationship is
between these variables. Correlation analysis revealed a very small, non-significant relationship between the outcome of parental cancer variable and benefit finding and, when entered at step 2 of the hierarchical multiple regression, outcome of parental cancer is a non-significant predictor. However, with the addition of the PCQ variables at step 3, outcome of parental cancer becomes a significant predictor. Moderator analysis was performed to attempt to explain this result; however, the findings were non-significant for all moderator interaction terms. Despite this, there is still evidence to suggest that some form of moderation may be occurring, as one of the interaction terms was approaching significance, and the variable representing cure (i.e., positive outcome) versus all other negative outcomes (i.e., treatment ongoing, spreading, recurrence or death) was a significant predictor of benefit finding in the moderator analysis.

10.3.3 Main finding seven: Benefit finding predicted depression, but not anxiety and well-being.

The multiple regression analysis found that benefit finding, emotional experiences, caregiver strain, and involvement in caregiving were all significant predictors of depression. The result suggests that benefit finding may serve as a protective factor, which may reduce the likelihood of developing depression, or reduce the severity of the disorder when it does occur. This supports the conclusion of the meta analysis by Helgeson et al. (2006) and several cancer-specific studies (e.g., Carver & Antoni, 2004; Dunn et al., 2011; Urcuyo et al., 2005) that benefit finding is associated with lower levels of depression. It is, however, acknowledged that the relationship between depression and benefit finding is not direct, suggesting that in this study benefit finding has functioned as a suppressor variable. This indirect relationship may also suggest the presence of a moderator or mediator variable and therefore future studies into this finding are warranted.

Study Two found that there was no relationship between anxiety and benefit finding, and as such benefit finding was not predictive of anxiety. This finding reflects the general consensus that the two concepts are unrelated (Dunn et al., 2011; Helgeson et al., 2006; Salsman et al., 2009;
It is, however, acknowledged that recent research, which has examined more specific anxiety-related concepts (e.g., state vs. trait anxiety, and event centrality), does seem to indicate some relationship between anxiety and posttraumatic growth (Boals et al., 2010; Loiselle et al., 2011). It is, therefore, suggested that further exploration of these concepts within the adult child cohort is warranted.

The regression analysis predicting well-being found that benefit finding was unrelated to well-being. This finding fits within the theoretical contention that posttraumatic growth represents a change in the individual’s core beliefs, so that they have a less idealistic, more negative view of the world (Janoff-Bulman, 1992). However, the empirical findings on the relationship between well-being and posttraumatic growth/benefit finding are mixed, with even reviews and meta analyses reporting conflicting findings. For example, Sumalla et al. (2009) in their review on posttraumatic growth in cancer concluded that the relationship between posttraumatic growth and well-being remained ambiguous. In contrast, wider meta analytic reviews have been conducted by Helgeson et al. (2006) and Sawyer et al. (2010), with both concluding that there is a positive relationship between benefit finding and well-being. While it may appear that the inconclusive findings may be an issue for cancer research, an extensive literature review of posttraumatic growth by Zoellner and Maercker (2006) also failed to find a consistent relationship between growth and well-being. However, it was suggested that research methodology may influence findings, with longitudinal studies typically finding a small but significant relationship.

In the present findings, the failure to detect a relationship between benefit finding and well-being may be related to the measures used (i.e., the PCQ is a new measure, and the WEMWBS has not been used in cancer research) and the cross-sectional design. It is also recognised that the majority of studies, which have found a positive relationship between well-being and benefit finding, have been conducted on the cancer patients themselves. It is entirely possible that adult children will report a different relationship between benefit finding and well-being. However, to date, there
has been no research specifically conducted into this topic, and therefore no conclusions can be drawn.

10.3.4 Main finding eight: The Parental Cancer Questionnaire (PCQ) as a reliable measure.

The final aim of the research conducted in this thesis was to determine the factor structure of the PCQ, and provide some evidence of the scale’s psychometric properties. Principal components analysis revealed that a three component model provided the best fit for the data, with the three components representing parental cancer benefits, emotional experiences, and caregiver strain. This three component structure contrasted with the expected structure that represented the themes from Study One.

Of most concern was the finding that the four benefit-related themes collapsed into a single benefit subscale, with only one personal development item being present. This suggested that overfactoring (Rummel, 1970) may have occurred. To ensure that the analysis of benefit items was not being influenced by the presence of the negative experiential items, a separate principal components analysis was performed on the benefit items only. This analysis did reveal a four component structure, however, the subscales were very short (two or three items each), and the reliability and validity of the subscales was questionable. In the light of this, it was concluded that a three component solution provided the best structure for the PCQ.

In terms of the PCQ’s emerging psychometric standards, the subscales report very good reliability coefficients all in excess of 0.85 (Garson, 2010). The scale was developed directly from data obtained from the target cohort, and, as such, it is high face validity. Initial analyses also confirm that the PCQ has adequate convergent and discriminant validity. Importantly, the benefit subscale correlates moderately with the Posttraumatic Growth Inventory (PTGI, Tedeschi & Calhoun, 1996), suggesting that the benefits subscale is assessing the same theoretical construct of the PTGI, a well respected and widely used measure in the field of posttraumatic growth. The emotional experiences subscale demonstrated strong significant positive correlations with a measure of distress at
diagnosis and a grief and loss measure, while the caregiver strain subscale also correlated in a moderately significant positive correlation with a measure of caregiver difficulties. In the light of the analyses performed, it is suggested that the PCQ is an appropriate measure, which assesses both the positive and negative dimensions of the parental cancer experience. The scale will be enhanced by further refinement through use in both research and clinical settings.

10.4 Directions for Future Research

The two studies in this thesis have answered the question regarding whether it is possible for adult children to perceive benefits from their experience with parental cancer, and have provided information regarding the types of benefits that arise. The studies have also begun to explore the predictors of benefit finding, and the relationship between benefit finding and psychological outcomes for adults whose parents have cancer. The findings of the thesis are viewed as a solid starting point, which can be used to guide future research, in addition to raising several key research questions. The avenues for future research, which were identified from Study One and Two, are reviewed below.

In regard to the types of perceived benefits, which are reported by the adult children of cancer patients, the current findings suggest that benefits are perceived to emerge across multiple domains, but particularly in the area of family. To a significantly lesser degree, personal development benefits may also emerge. Two important research paths emerge from these findings. Firstly, it is important to further investigate the types of personal development benefits that adult children do report. It is strongly recommended that such investigations adopt a qualitative approach to ensure the collection of rich, detailed data from the perspective of participants. Furthermore, the collection of qualitative data will allow a discussion of the types of personal development benefits reported, allowing researchers to explore the significance and meaning such benefits have, whilst also exploring possible explanations of why such outcomes may not be as prevalent as other benefits emerging from the parental cancer experience.
The second key area of future research is further exploration of the finding that adult children seem to report greater levels of family-related benefits, which is potentially different from the findings of other studies based on spouse and patient cohorts. Future research needs to replicate aspects of the current study to allow for the examination of the types of benefits reported by adult children to confirm or refute the suggestion that adult children benefit mostly in regard to family from their parent’s cancer. Further insight into this area will also be gained through studies, which examine differences between adult children, spouses and cancer patients, to determine whether there are differences in the degree to which certain types of benefits are developed. It is, therefore, suggested that studies that collect data from entire family units would be beneficial to allow a direct comparison of the types of benefits reported, based on the relationship to the patient. Furthermore, if such studies collected data on variables, such as family cohesiveness, communication, and conflict, there is the potential to examine whether perceived family-related benefits are reflected in family interactions.

In regard to posttraumatic growth theory, the current findings, particularly Study One, suggest that benefit finding may be both an outcome and an illusory coping mechanism, with each type being evident at different times during the parental cancer experience. This supports the Janus Face model of growth proposed by Maercker and Zoellner (2004; Zoellner & Maercker, 2006). However, it is noted that this thesis was not designed to test theoretical models of growth; rather, the data were examined to determine whether there seemed to be any fit between the findings and the current theoretical explanations of posttraumatic growth. It would be beneficial for future studies to specifically examine the utility of theoretical explanations of posttraumatic growth in relation to benefit finding in parental cancer. For example, there is much to be learned regarding the type of cognitive processing that is undertaken by adult children, and it is still unexamined whether parental cancer brings about changes in core beliefs. It is, therefore, recommended that future studies include measures to assess
cognitive processes, such as rumination, coping mechanisms, and changes to core beliefs.

In further exploration of the applicability of the Janus Face model, it is also noted that study designs will need to be longitudinal to gauge whether different cognitive processes are occurring at different times throughout the experience, and whether different types of benefits are reported at differing time frames. It is also suggested that qualitative data be incorporated into data collection procedures, as it was the description and elaboration of benefits in Study One that helped to identify the possibility of benefits as an illusory coping mechanism.

Study One suggested that there was a relationship between the emotional experiences during parental cancer and/or involvement in caregiving and the number of benefits reported. Study Two examined this relationship further, and confirmed that the emotional intensity of the experience is predictive of benefit finding, with higher benefits being reported by individuals who report higher emotional disturbance. There is also partial support that engagement in caregiving is related to benefit finding, specifically, the ability to identify rewards and satisfactions arising from caregiving, was linked to higher benefit finding. This pattern of relationships and prediction needs to be replicated in future studies, with the possible examination of other variables identified by other researchers as potentially influencing the degree of benefit finding. For example, coping responses were identified by Manne et al. (2004) as being predictive of posttraumatic growth, and the role of cognitive processing, such as rumination and positive reinterpretation, have not been examined in the adult child cohort. The inclusion of these variables would not only potentially expand our knowledge on the predictors of benefit finding, but also add to our theoretical understanding of the phenomena in adult children of cancer patients. This is important, as Manne et al. (2004) found that patients and spouses had entirely different variables predicting posttraumatic growth. Therefore, it is important not to assume that variables, which have demonstrated predictive utility in spousal and patient studies, will have applicability to the adult child cohort.
The finding that carer satisfaction was predictive of benefit finding represents a relatively new area of knowledge. Very little prior research has examined the relationship between the two variables, and no studies have investigated the predictive utility of carer satisfaction on benefit finding. This is, therefore, identified as an area requiring further study, with the aim of confirming the relationship between the variables, and then further examination of the role of cognitive factors in the development of such outcomes. For example, it may be that positive reappraisal is crucial to the development of both benefit finding and carer satisfactions, and therefore may potentially mediate the relationship between the two. Alternatively, dispositional traits, such as optimism, or environmental factors, such as social support, may also contribute to the relationship between benefit finding and carer satisfaction, and therefore are variables worthy of inclusion in such studies.

Existing studies by Compas et al. (1994) and Oktay (2005) have suggested that illness-related variables may also be important in the prediction of benefit finding. While the present study did consider the outcome of parental cancer (as suggested by Oktay, 2005) and some additional illness variables (i.e., duration of illness, gender of parent), only the outcome of parental cancer was a significant predictor of benefit finding. However, the mechanisms underpinning this prediction are unclear, as demonstrated through the non-significant moderator analysis. It is, therefore, strongly recommended that future studies examining the prediction of benefit finding include the outcome of parental cancer in their analysis to help bring to light the role this variable plays. Replication of the current study on a larger sample size may also help to clarify the role of this variable in predicting benefit finding. Additional illness variables that may be worthy of inclusion are the perceived stressfulness and the perceived seriousness of parental cancer (Compas et al., 1994), the type of parental cancer, and the parent’s age at diagnosis.

It is important to stress that future studies need to employ longitudinal designs, wherever possible. Much of the ambiguity regarding
the role of benefit finding in the prediction of psychological outcomes, such as depression, anxiety and well-being, is due to inconsistent results being obtained from cross-sectional studies. It is acknowledged that the studies in this thesis employed a cross-sectional design themselves. However, considering that research into benefit finding in the adult children of cancer patients is a relatively unresearched area, it seemed prudent to conduct some confirmatory studies, before employing larger longitudinal studies that require a much greater commitment from participants. Now that this thesis has contributed much needed knowledge into this area, future research can begin to explore the relationships identified in this thesis through longitudinal designs. Such future studies will be able to assess the validity of theoretical models, examine changes in benefit finding over time, and assess the longevity of benefit finding in the target cohort. Perhaps most importantly, longitudinal studies can add great insight into the relationship between benefit finding and psychological outcomes at various points throughout the parental cancer experience. This type of longitudinal knowledge would be very important, as the current study provides very little clarification of the role of benefit finding in relation to depression, anxiety and well-being. It is acknowledged that longitudinal studies are inherently more difficult to conduct; however, the value of the data they would contribute to the field would be significant. The consideration of potential moderator variables (e.g., outcome of illness, centrality of event, posttraumatic stress symptoms), which may enhance our understanding of how benefit finding may indirectly influence psychological outcomes, would be a valuable addition to future research designs. Finally, it is recommended that, at this point, such studies use measures that include multiple domains of benefit finding, as research by Kim et al. (2007) suggests that different dimensions of benefit finding contribute differently to psychological outcomes, and such differences cannot be examined, if only overall benefit scores are used.

Finally, there are several studies required in relation to the development of the Parental Cancer Questionnaire (PCQ). Firstly, the component structure of the PCQ should be confirmed in a study with a larger sample size. This is important, as it would confirm or refute the
combination of benefit items into a single component. Future principal components analysis may also see the inclusion of additional personal development items into the benefit subscale, as concerns are noted regarding the virtual elimination of this category of benefits from the PCQ. It is, therefore, recommended that, at this stage, the original version of the PCQ be used in research, until the component structure and content has been confirmed or refined.

Once the component structure of the PCQ is finalised, studies will need to be conducted to develop the PCQ’s normative data, and further demonstrate the scales reliability and validity. Essential to establishing normative data is ensuring adequate sample size, and a large sample will be required to ensure that adequate representation of key groups is present. For example, gender norms are required and, with the suggestion that the outcome of parental cancer may play a role in benefit finding it is essential to ensure that adequate numbers are present in all outcome groups (i.e., cure, treatment ongoing, spreading/recurrence, bereavement). It may also be important to examine whether cancer type affects response to the PCQ, as normative standards may need to be developed based on cancer type. For example, cancers, which have a strong genetic link (e.g., breast and bowel cancer), may be potentially more distressing than cancers with no genetic risk, as genetically-linked cancers may present challenges to the adult child’s own mortality, and therefore these cancers may be perceived as more traumatic. Furthermore, if the PCQ is to be used in clinical settings, it will be important to establish norms for clinically significant groups, such as individuals meeting the diagnostic criteria for depression and PTSD.

In terms of psychometric standards, future studies may wish to establish the test-retest reliability of the PCQ. This will be especially critical for the use of the PCQ in longitudinal studies. The PCQ’s validity will be refined in studies that include measures of benefit finding and social desirability, and corroborating evidence of benefit finding, such as reports of growth from other family members. The PCQ’s discriminant validity would be further established, if relationships could be demonstrated.
between the PCQ and other variables known to be related to benefit finding, such as optimism, social support, positive affect, and coping.

10.5 Implications for Clinical Practice

The data obtained from Study One, regarding the negative experiential aspects, contains several insights that are important for clinical practice. The strong prevalence of emotional impact and grief and loss issues are significant indicators that some adults, whose parents have cancer, face significant psychological challenges that they may be ill equipped to deal with. This reaffirms the argument of Rait and Lederberg (1990) that the family members of cancer patients have their own psychological needs, and can be conceptualised as second-order patients. The challenge for clinicians is to ensure that the adult child has access to support services that meet these individual needs. For example, the participants in Study One reported a sense of isolation, which may have exacerbated their emotional experiences, as they felt there were very few people they could turn to for support. It is, therefore, recommended that appropriate support services be developed and promoted, so that adult children may make contact with others in similar situations to increase their connection with others, and reduce their perceived isolation.

Study One also demonstrated that parental cancer can challenge the adult child’s sense of stability by highlighting their parent’s vulnerability, eliciting rumination on death, and disrupting familial relationships through increased conflict, anger and resentment. There are also case examples that highlighted that the grieving process can be long, and many issues surrounding loss can be unresolved. While most large cancer support agencies do offer services to family members, it is significant that only two participants made reference to using such agencies, and that contact was to obtain more information regarding the disease and treatment, rather than seeking support for their own psychological needs. It is, therefore, strongly recommended that cancer support organisations assess the strategies they are employing to reach adult children, and consider flexible support options, as it is noted that the adult child can experience high levels of role strain throughout their experience of parental cancer.
The findings of Study Two suggest that benefit finding may act as a protective factor that helps to prevent or minimise depression in the adult children of cancer patients. However, such a result must be interpreted cautiously from a clinical point of view, especially as the relationship between benefit finding and depression is not direct, but rather suggestive of a suppressor variable. This lack of a direct relationship strengthens the argument of researchers and theorists, who caution that the widespread promotion of the development of benefits in clinical interventions may be premature and detrimental, in the light of our current understanding of the relationship between benefit finding and psychological outcomes. It is, therefore, recommended that clinical interactions embrace benefit finding when it emerges spontaneously with a client, and that any specific interventions are aimed at enhancing cognitive-based coping, rather than increasing or bringing forth benefit finding. Furthermore, it is stressed that clinicians follow the advice of Calhoun et al. (2010), and adopt the role of a supportive companion through the adult child’s grief, respecting that growth may not occur in some individuals, and highlighting that, when it does arise, it is attributed to the client’s struggle with their loss, rather than perceived as a direct outcome of the loss itself.

In terms of well-being, Study Two found that lower levels of well-being were associated with increased levels of caregiver strain. This implies that, to improve well-being amongst adult child caregivers, steps needs to be taken to reduce caregiver strain. One relatively easy way to address this is to ensure that caregivers are aware of existing support services within their local area. Government supported respite schemes, subsidised home care and community nursing need to be available and accessed as required. Furthermore, much of the strain evident in Study One appears to be related to conflict within family relationships, arising from perceived inequity regarding how caregiving responsibilities were distributed within family networks. It is, therefore, suggested that family-based interventions may be helpful to address these issues.
Finally, it is proposed that the PCQ may become a very valuable clinical assessment tool. The PCQ was developed directly from data from the target cohort and, therefore, it assesses the experience from the perspective of the adult child. The inclusion of both positive and negative dimensions will allow for more comprehensive insight into both the overall impact and growth that has arisen, while the caregiver strain items provide an understanding of the practical changes that have also impacted on the adult child. The PCQ is unique in the area of parental illness, and it may assist clinicians in gaining a comprehensive assessment of key issues is a single, relatively short measure. The clinical value of the PCQ will be enhanced, once normative data for key clinical sub-groups (e.g., depression, PTSD) are established.

10.6 Conclusion

Overall, the findings of both the qualitative and quantitative studies revealed that benefit finding is a common outcome for adults who experience having a parent with cancer. The types of benefits reported were varied; however, family-related benefits emerged as a strong area of positive change. Additionally, it was found that context of benefit finding was important, as both studies indicated that the emotional experiences, which occurred throughout the parental cancer journey, were critical for growth to occur. It is, therefore, concluded that positive benefits may arise, however, they do so in the context of emotional struggle and loss.

The quantitative study also examined the role that benefit finding plays in the psychological functioning of adult children. It was found that benefit finding may act as a protective factor for depression, potentially reducing the likelihood of the development of this affective disorder, or reducing its severity. However, benefit finding was unrelated to anxiety, or well-being. The failure to find a relationship between benefit finding and anxiety or well-being was not unexpected, considering the research design, and the null findings strengthen the argument that psychologists and researchers should not conceptualise benefit finding as the panacea to improve well-being, and alter negative psychological outcomes arising from traumatic experiences.
Finally, both studies have led to the development of the PCQ, a scale with wide clinical and research utility. The strengths of the PCQ are that it is specific to the parental cancer experience, it was developed based on data provided by the target cohort, and it addresses a void in the assessment measures available. The PCQ has demonstrated excellent reliability in Study Two, and promising validity data has been presented in this thesis.

In conclusion, the findings from the studies undertaken in this thesis clearly demonstrate that parental cancer impacts on the psychological functioning of adult children of cancer patients. This impact appears life-altering in both positive and negative ways, and may potentially last for many years, following the parental cancer experience. As such, the findings reported from Study One and Two make important contributions to the development of knowledge in an under-researched area. It is hoped that this new knowledge can be expanded, debated and most importantly utilised, in both research and clinical settings.
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Appendix A: Published Journal Article from Study One

Parental Cancer: Catalyst for Positive Growth and Change

Janelle V. Levesque and Darryl Maybery

Abstract
Cancer is a disease that affects the entire family, with each member having unique psychological needs. To date, there has been limited research into the effect of parental cancer on adult children. Furthermore, existing research has largely overlooked the possibility of positive psychological growth in the adult offspring of cancer patients. To investigate the perceived benefits arising from parental cancer, 11 interviews were undertaken with adult children whose parents had been diagnosed with cancer, to discuss their experiences of their parent’s illness, and their evaluation of both the positive and negative changes that had arisen. All participants were able to identify positive outcomes in direct response to their parent’s cancer. Frequently suggested changes included improved relationships with their sick parent, an increased emphasis on family, revised life priorities, and personal development. The implications of these findings, their link to posttraumatic growth theory, and avenues for future research are discussed.

Keywords
cancer, psychosocial aspects, emotions / emotion work, families, illness and disease, experiences; relationships, parent-child

Cancer is a disease of global significance, with an estimated 2.7 million new cases and 7.6 million cancer-related deaths occurring in 2008 (Cancer Research UK, 2011; World Health Organization, 2011). It is estimated that more than three million new cancer diagnoses were made in Europe in 2006 (Ferlay et al., 2007). 1.5 million new cases in the United States in 2010 (American Cancer Society, 2010), and nearly 180,000 new cases will be diagnosed in Canada in 2011 (Canadian Cancer Society, 2011). Although the number of cancer-related deaths are high (e.g., 156,000, or one in four deaths in the United Kingdom in 2008; Cancer Research UK), the survival rate has consistently increased, with 5-year survival estimates now ranging from 51% in the United Kingdom to 66% in the United States (American Cancer Society; Cancer Research UK). The incidence of cancer in Australia, where this study was conducted, remains high, with more than 100,000 new cases diagnosed each year (Australian Institute of Health and Welfare, AIHW, 2008). Cancer was recorded as the main underlying cause of death in Australia for the period of 2002 to 2004, and it accounts for approximately 28% of deaths each year (Australian Bureau of Statistics, 2006). The 5-year survival rate has, however, increased; approximately 63% of cancer patients will reach this survival milestone, thereby resulting in an increased prevalence of the disease in Australian society (Tracey, Chen, Baker, Bishop, & Jels, 2006). Consequently, a growing number of patients and their families are living with the disease, its consequences, and the fear of recurrence for longer periods of time.

Over the last 20 years it has been recognized that cancer is a disease that affects the entire family, and that family members are “second-order patients” with unique needs (Arnaez, Gabos, Ballellas, & Rutledge, 2010; Rait & Lederberg, 1990). Although there is a growing body of literature reporting on research examining the impact of parental cancer on young children and adolescents, there have been very few studies focused on the effects of parental cancer on adults. This is a significant void, because many cancers typically occur in people aged 50 years and older; for example, 85% of prostate cancer cases occur in men aged 65 and above (Cancer Council Australia, 2010), and 76% of breast cancer cases occur in women aged 50 years and older (AIHW and National Breast & Ovarian Cancer Centre, 2009). Considering that in the majority of cancer cases the patient’s children are adults, steps must be taken to increase our knowledge and

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Understanding of how cancer affects this cohort, to ensure that support agencies are able to develop appropriate services to meet their needs. Although it can be argued that most adult children live independently from their parents, it should not be concluded that the impact of parental cancer is minimized simply because the dependent child-parent relationship is no longer present. Logan and Spitzer (1996) argued that adult children feel a great deal of familial responsibility when faced with a sick parent. Others have found that caregiving is linked to role strain, increased depression, and anxiety among children caring for parents with cancer (Amada & Hayman-White, 2001; Ravelis, Karras, & Pretzer, 1999; Ravelis, Karras, & Seigel, 1998).

Previously, researchers have tended to focus on the identification of psychopathology arising from parental cancer. For example, Kissane, Bloch, Burns, McKenzie, and Postering (1994) examined psychological morbidity in family members of cancer patients receiving palliative care, and found that 20% of children met the diagnostic criteria for depression using the Beck Depression Inventory (Beck, Steer, & Garbin, 1988). An additional finding was that the children reported significantly higher levels of anger compared to their parents (both sick and healthy), potentially indicative of higher levels of anticipatory grief (Kissane et al.). A limitation of the study, however, was that the children in the survey were aged 12 and above, with no information provided regarding their age breakdown; therefore, care must be taken in generalizing this result to the adult cohort.

Moshier and Danoff-Burg (2005) conducted a review of the psychosocial impact of parental cancer and concluded that anxiety and depression were developed by a “sizable minority” (p. 365) of adult children. Furthermore, Moshier and Danoff-Burg highlighted that, for some individuals, the diagnosis of a parent with cancer gave rise to symptoms akin to posttraumatic stress disorder (PTSD). This review highlighted that the majority of studies have examined the psychological outcomes of the children (typically daughters) of breast cancer patients, in part because it is thought that the potential for the genetic heritability of breast cancer might increase the likelihood of PTSD in the daughters of breast cancer patients (e.g., Lindberg & Wellisch, 2004). Smith, Redd, Peyer, and Vogl (1999) conducted a wider examination of the link between cancer and PTSD, and found that clinical PTSD was present in the parents of childhood cancer patients, further suggesting that the stress associated with cancer can significantly impact on individuals other than the patient. Although studies such as these provide some insight into the experience of parental cancer, we argue that the narrow focus on psychopathology fails to capture the breadth of the experience. Consequently, there is a lack of knowledge concerning the potentially positive outcomes that might emerge.

Trauma- or stress-related growth theory attempts to explain the emergence of positive outcomes from seemingly negative and traumatic events. Affleck and Teasman (1996) have suggested that negative events trigger the need for psychological restructuring, or a reinterpretation of the traumatic event, so that it can be perceived as "beneficial" for the individual. Janoff-Bulman (1992) argued that highly stressful events might make the individual question his or her core beliefs about the world, giving rise to an opportunity for change and growth. Similarly, Tedeschi and Calhoun (1995, 2004) proposed that growth occurs when the individual recognizes that a new reality has arisen from the stressful event. Therefore, posttraumatic growth is not simply a return to pretrauma functioning, but rather is an improvement in some area of the individual’s life (Tedeschi & Calhoun, 2004).

The notion of deriving benefits from cancer has recently emerged in the psychological literature (e.g., Lelorain, Bemouin-Antignac, & Florin, 2010; Saloman, Segestrom, Brechting, Carlson, & Andrejczuk, 2009; Schulz & Mohamad, 2004). Thornton (2002) proposed that patients derive a variety of benefits from their illness in three broad areas, including benefits associated with one’s life perspective, one’s interpersonal relationships, and the self. Several researchers have confirmed that such benefits are present in the spouses of cancer patients, suggesting that growth can occur in individuals other than the patients themselves. For example, Thornton and Perez (2006) examined posttraumatic growth in prostate cancer patients and their spouses, and found that both groups reported modest levels of growth; however, the growth was unrelated to their reported quality of life. Weiss (2002) studied the spouses of breast cancer patients and found that 88% of the spouses reported positive changes, typically in the areas of enhanced relationships and an increased appreciation for life. Mane et al. (2004) examined the predictors of posttraumatic growth in partners of breast cancer patients over an 18-month period and found that age, higher levels of intrusive thoughts, a higher use of emotional processing, and positive reappraisal predicted the level of posttraumatic growth.

There have, however, been very few studies conducted to specifically determine whether positive benefits occur among the adult offspring of cancer patients. Moshier, Danoff-Burg, and Braunzer (2006) reported that the daughters of breast cancer sufferers do report posttraumatic growth at levels similar to breast cancer patients. Unfortunately, Moshier et al. did not detail the degree of benefits found in the posttraumatic growth domains, and used a relatively small sample by quantitative standards (n = 30). As such, the findings provide very little information other than simply confirming that positive changes are possible in response to parental cancer. Kim, Schultz, and Carver (2007) explored the existence of perceived benefits...
among cancer caregivers using a much larger sample. Although the majority of the sample were spouses, 34% (n = 265) were other adult family members, such as adult children. In this study, the researchers found that positive outcomes among the adult offspring were possible in the domains of acceptance, empathy, appreciation, family, positive self-view, and reprioritization. Kim et al. (2007) also found that the perceived benefits were higher among caregivers who had higher levels of social support, and that the various types of benefit might influence their level of depression. Notably, the nature of the family relationship (i.e., spouse vs. other family member) did not significantly predict benefit finding (Kim et al.), which suggested that the level and type of benefits derived from the cancer experience are similar for spouses and adult children. However, additional investigation is needed before firm conclusions can be drawn.

In addition to the two studies outlined above, there is also data from qualitative studies into the general experience of parental cancer and cancer caregiving that suggest that benefits might be present in the adult children of cancer patients (e.g., Oltay, 2005; Tarkam, 1999; Wong, Usher, & Perez, 2009). Although benefits have not been the focus of these studies, their data suggest that improvements in relationships, changed life priorities, and personal development are possible outcomes from having a parent with cancer. In the light of the lack of information in the area, we aimed to investigate the experience of parental cancer, with a particular focus on identifying the psychological and social benefits that might arise.

Method

We used a qualitative methodology for data collection and analysis in an attempt to gain an insight into the experience of adults having a parent with cancer. We deemed this the most appropriate method because of the limited research conducted with this cohort, and desired to capture the core elements of the experience. We employed an interpretive phenomenological analysis (IPA) approach to enable a detailed examination of the experience as it is perceived by those who live through it, hence capturing the "human" dimensions of this aspect of health (Thorne, 2011). IPA is grounded in two philosophical schools of thought: phenomenology and symbolic interactionism. Phenomenology focuses on the lived experience of individuals, examining the world as it is perceived by people, and gaining an insight into how people understand their world (Wulff, 2001). We aimed for the study to provide both a description of the phenomena of parental cancer and the articulation of the meaning derived from people's lived experience (Greenewald, 2004). Through the second philosophical foundation, symbolic interactionism, researchers aim to understand the lived experience of people through an examination of interactions both within (e.g., thoughts, interpretations) and between individuals and groups (Ephros & Greene, 1991). In symbolic interactionism it is acknowledged that people experience the world through dynamic social processes that have the potential to change the individual by altering his or her interpretation and understanding of the world (Charm, 1990). We believe it was critical to use a philosophical approach, which acknowledged the significant role of interactions in human understanding, because the topic of investigation was how illness in one individual affects the psychological functioning of another, while also considering the broader context of the family unit.

Participants

Participants were recruited for involvement in the study through Charles Sturt University's daily electronic news posting, or through regional radio exposure. Participants were eligible for inclusion if they met the following criteria: they were aged 18 or older at the time of diagnosis; the diagnosis of parental cancer occurred at least 12 months previously; and, if bereavement had occurred, it had taken place at least 6 months prior to their participation in the study. Eighteen volunteers contacted the researchers; however, seven failed to meet the eligibility criteria and were excluded, leaving a final sample of 11 participants. Nine of the 11 participants were women, and ages ranged from 24 to 52 years, with an average age of 41 years. Forty-six percent of the diagnosed parents were mothers, 36% were fathers and, in 18% of the cases, both parents were diagnosed with cancer. The types of parental cancer included breast, prostate, multiple myeloma (two cases of each type), bowel, brain, melanoma, pancreatic, ovarian, chorioderma (malignant bone cancer in the skull base and/or spine), and lymphocytic leukemia (one case of each type). Most participants (10 out of 11) had siblings, ranging in number from one to four, with a modal number of three siblings. Seven of the participants were involved in caring for their parent in some capacity (e.g., they were either a primary carer, part of a family care team, attended medical appointments, or were involved in treatment decisions).

Data Collection

We employed semi-structured interviews to collect data. Interviewing is well suited for the exploration of the deeply personal experience of parental cancer, allowing the researcher to gain an insight into "subjectivity, voice and lived experience" (Rapley, 2004, p. 15). Furthermore, in semi-structured interviewing it is recognized that research participants are active meaning makers and the "experts" on the topic under investigation (Smith & Osborn, 2003). The first author (L. Vesque) conducted all interviews, and
the semistructured approach provided a flexibility that allowed the pursuit of interesting and relevant topics that emerged from the participants’ accounts of their experiences.

The interview schedule was divided into several sections: (a) experiencing parental cancer (e.g., Tell me about your parent’s cancer); (b) familial relationships (e.g., Can you describe how you believe parental cancer has changed your family, if at all?); (c) coping (e.g., How did you adjust to your parent’s cancer?); (d) cancer and adjustment-related cognitions (e.g., What are some of the cancer-related thoughts or beliefs you used to help you deal with your parent’s cancer?); and (e) personal health behaviors (e.g., Do you think that your parent’s diagnosis of cancer has altered the way you look at your own health?).

We acknowledge that no question was asked that specifically mentioned perceived benefits, despite this being the particular focus of the study. It was our opinion that the area of investigation was a particularly sensitive subject, and that questions implying that the participants could benefit from the suffering of their parent might cause offense. To overcome this, we asked a variety of general questions on the experience of parental cancer and, when positive changes were raised by participants, additional questions were asked to gain insight into those changes and to determine the meaning that the participants had developed surrounding such changes.

Participants were asked to contact the first author to arrange a time and place for the interview. The participants determined the location of the interviews (e.g., work offices, homes). The interviews ranged from 20 to 75 minutes in duration. All interviews were recorded and transcribed verbatim, with all identifying information being removed to protect participant anonymity. The study had the approval of the Charles Sturt University Human Research Ethics Committee. Because of the sensitive nature of the topic, the ethical procedures implemented prohibited the participation of individuals whose parents had been diagnosed within 12 months, or who were recently bereaved. Additionally, all participants were provided with contact information for two counseling support agencies, a cancer-specific hotline available during business hours, and a general counseling service available 24 hours a day.

Data Analysis

The first author analyzed the transcripts using IPA as outlined by Smith and colleagues (see Smith, Jarman, & Osborne, 1999; Smith & Osborne, 2003). The analysis began with a single transcript being read several times to identify important points of interest, recurring topical sentiments, and analytic impressions. The next stage of the analysis involved listing and articulating emerging theme titles, and an examination of the emerging themes for possible connections, which led to the creation of a master list of themes for that transcript. Each transcript was treated as a “new first case,” and the above process was repeated for each case, with efforts being made to minimize the influence of themes identified in prior cases on each analysis. Once each transcript was analyzed, the authors read the master lists together, and noted similarities and differences.

The first author made journal entries throughout all stages of the data analysis process, reflecting her interaction with the text. This diary was used to note possible interpretative options, uncertainties regarding the interpretation of the data, insights into how the first author’s presuppositions might have influenced the data interpretation, her emotional reactions to the data, and points of interest to pursue in additional readings of each transcript. The first author reviewed the diary regularly throughout the data analysis process to ensure that all impressions and interpretations of the data were considered. The reflective journal was one strategy that we employed to enhance the rigor of the research, with additional strategies outlined below.

Rigor

We ensured that several systems were built into the research design to make the procedure rigorous and transparent. Pure phenomenological studies require researchers to suspend their prior knowledge, beliefs, and presuppositions through the process of bracketing (Laverty, 2003). We argue, however, that the suspension of presuppositions is difficult to achieve, and therefore a more authentic approach is to acknowledge the role that researcher beliefs, values, and identity play in the interpretation of data (Denzin, 2003). Because the first author had experienced parental cancer as an adolescent, it was essential that she acknowledge her presuppositions. We also share Holloway’s view that prior experience of the researcher with the phenomena under study might enhance the research process through the use of common language and data sharing (Holloway & Biley, 2011). Holloway (in Holloway & Biley) also argued that qualitative research needs the voices of both participant and researcher for the interpretation of meaning. The first author engaged in a process of self-reflection, which involved the articulation of the beliefs and biases that had arisen from her experience, before the commencement of data collection. Throughout the data analysis process, she regularly reviewed these presuppositions, and self-evaluation was conducted to determine whether personal bias had distorted the data interpretation. The first author and a fellow academician also engaged in regular discussion of cases throughout the data analysis phase to ensure rigor. Both parties independently analyzed several cases, and followed up with a discussion of themes and interpretative concerns. A high degree of similarity in
terms of the identified themes was found, and the process provided an opportunity to discuss ways in which researcher bias might have been present in the interpretation of the data. This process was viewed as a credibility check (Elliott, Fischer, & Remnie, 1999), rather than an attempt to establish interrater reliability. The final strategy we employed to ensure methodological rigor was the explicit examination of negative cases. Negative cases are sentiments expressed by participants that do not agree with the dominant view of the data set (Willig, 2001). The value of negative cases is that they highlight areas of difference, which assist in evaluating the suitability of data interpretation. We identified six negative cases, and these cases are highlighted in the results presented in this article.

Results

The analysis of the data revealed that, although perceived benefits were present to some degree in all participants, such benefits were clearly related to the struggle that the individual had traveled through as a result of having a parent with cancer. The emotional upheaval and life disruption that the illness had on the individual’s life provided the context in which to appraise the benefits that emerged. Therefore, the first theme that emerged was emotional experiences arising from parental cancer. Four benefit themes were identified, which included transforming the relationship with the sick parent, family matters, altered life priorities, and personal development.

Emotional Experiences Arising From Parental Cancer

Most participants mentioned the notion of disruptions in their normal life caused by their parent’s cancer, and the emotional reactions that accompanied these changes. For some participants, the impact of the diagnosis and treatment was very intense. One participant described the impact of parental cancer as “the biggest thing in my life, especially the last few weeks; they were just dreadful.” Another stated that the experience of having both parents diagnosed with cancer within 18 months of each other was “really quite traumatic.” Some participants used language that indicated that the impact and ensuing disruption were so intense that their lives became quite enmeshed with their parents, to the point that they would refer to themselves as the patient (e.g., “So I am still up to the second last of the hormone needles at the moment”) or use the collective pronoun “we” to describe treatment activities (e.g., “No, she has finished her [chemotherapy] session; yeah, so that is where we are up to”).

Participants reported a range of emotional reactions, which included shock (e.g., “I didn’t know that it would happen to us”), anger (e.g., “My workplace was very sympathetic and supportive, but people would say things and I would get so angry”), uncertainty (e.g., “For me at different times, a sense of when will this end? I wish it would end either way in some ways.”), frustration (e.g., “He goes okay for a little although, and then the next thing will hit, and yeah you go through that, and it’s just a matter of waiting”), and sadness (e.g., “I think I am sadder than I used to be, and I am sure a lot of that has to do with saying goodbye to my mum [mother].”)

The emotional reactions were changeable throughout the disease progression, with often intense reactions experienced at the beginning, followed by longer-term sadness, grief, and loss as the disease progressed. One participant reflected this change in emotional experience when she described the journey as an “emotional rollercoaster.”

The participants expressed a sense of guilt throughout the interviews. Guilt was often multifaceted, and triggered by numerous situational aspects, such as wishing the experience would end, issues of care, or perceived inappropriate reactions on their part. One participant, whose father’s leukemia was marked by unpredictable periods of decline, described how this pattern made it difficult to plan her own life, and commented, “You get frustrated, then you feel, sometimes you wish that he wouldn’t get better, that it would just be better if it were all over. And then you feel guilty for feeling like that, I guess helpless.”

The participants raised significant issues of grief and loss, and many of these issues stayed with participants for long periods of time. One participant reflected that “this will be the fourth Christmas without her, and it’s like that’s too many, it shouldn’t be that far along, and it is hard to deal with that day to day sometimes.” For some participants the realization that their parent was not infallible, and would not live forever, challenged their sense of security and place in the world. For example, one participant stated, “I learned that they are human, because when you see your parent, when you are young you see them as being there forever, which they are not.” Participants also identified losses (apart from the actual death of a parent), which included changes to the parent’s behavior and cognitive functions (e.g., “She has always been really smart and good with words, and she couldn’t communicate properly. She couldn’t get the right words, and that was really distressing for her and us”), and reduced contact with the healthy parent (e.g., “When he is bad Mum can’t leave him. When he is not bad she is afraid to leave him in case something happens”). It also emerged that the grief which arose from parental cancer continued to impact on the adult child long after the death of the parent. As one participant revealed, “I don’t think I have ever really come to terms with that sort of grief; it is all sort of simmering there in the background.”
Transforming the Relationship
With the Sick Parent

One of the strongest themes to emerge from the data was that parental cancer prompted many participants to change their relationship with their sick parent. For some participants, the cancer diagnosis provided an opportunity to resolve old conflicts and grievances and, in doing so, to develop an enhanced sense of connection with their sick parent. For example, one participant felt that his father had disapproved of his career in professional sport; however, he perceived that, after the cancer diagnosis, his father had reevaluated this position, which led to an increased sense of approval and respect. He stated,

He never thought [sports] coaching was a job and now, when I told him about, I had an opportunity to go [overseas], and get a job... coaching and he is eager for that now... He is much happier for me to go and do things that I want to do... Now he is more into me making happy decisions. I guess, so that is the biggest change, or one of. We do things now we didn’t before. We worked, we talked about working, but we have played golf, we have talked about buying a boat together.

Other changes that were noted by participants included "getting to know each other adult to adult," the sharing of life stories, and an enhanced understanding between parent and child, so that overt communication was not always needed (e.g., "I know how she is feeling without her saying"). Among participants who already had a good relationship with their sick parent, it was reported that a sense of increased closeness developed, or an open acknowledgement emerged of how significant the relationship was with their parent. One participant described this change:

The way that I felt about her and wanting to be with her changed... I suppose more of an appreciation of her, not a deepening of love or affection, probably more deconstructive in it, and much more in giving to her rather than taking all the time.

The enhanced connection described above has continued for many years after the cancer experience, with the participant and mother living together at the time of interview and reporting a strong relationship. This suggested that the changes that emerged during the intense period of parental illness might stand the test of time, and might have continued to have positive impacts on the individual.

Another area in which change emerged was in a respect and appreciation of the sick parent, with cancer providing a context within which the individual was able to evaluate the importance of their parent. One participant described her mother as "the core and the lynchpin and the concrete underflooding of the whole system [of her family]." For some participants who lost their parent, they developed a respect for the way their parent had approached their death. One participant described his admiration for his mother in the way that she handled the practical aspects of her death (e.g., disposal of assets, care decisions). Another participant described her admiration of her mother's behavior when she commented, "Whatever she did go through, she did with a lot of dignity."

Family Matters

Participants acknowledged that living through the experience of parental cancer provided an opportunity to reflect on the importance of their family in their lives, and altered their relationships with other family members. They frequently mentioned an increased valuing of their family, which in essence arose from the recognition that their family played a central role in their life. They became increasingly aware of the important connections and love that their family provided. This was accompanied by the recognition that the family should not be taken for granted, but rather required attention and devotion. For example, one participant reflected,

I guess it has... made me more aware of family and the importance of being, of doing things that you need to do with your family, spending the time with your family, telling them that you care about them.

Both men in the study mentioned an increased emphasis on family. One asserted that the meaning that he had taken from his parent's cancer was "doing better at family stuff," which he defined as spending time with his brothers, sisters, niece and nephews. The experience of his mother's breast cancer led the other man to reflect on his relationship with his wife and children. He described his (then) current relationship with his own family as closer, and said that he spent more time with them than before the cancer experience. He acknowledged, however, that during his mother's cancer there were marital issues and disruption to his family life, because he struggled to balance caring for his mother with his responsibilities to his wife and young children. Therefore, we interpreted the data to suggest that although the cancer experience did lead to an increased awareness of the importance of family, in reality, it also created strains that needed to be reconciled.

Participants also reflected on beneficial changes in their relationships with other family members, such as the healthy parent, their siblings, and extended family members. Changes to the relationship between healthy parent and adult child often involved an increase in the care for
or worry about the healthy parent; however, it was also marked by enhanced communication and increased affection. One participant stated, "I think I can tell her [healthy parent] I love her more than I used to be able to, and she can say that to me. . . . We can talk about stuff, about Dad too." Another participant described the increased affection between herself and her father, which was identified as a startling change in their pattern of interaction:

"I am even shocked when sometimes he leans in for a kiss. You know, he has never been that type of man, and when he shows affection—like he puts his hand on my knee or a hand on the shoulder—. . . or he does cuddle me; he does stand there and cuddle me."

The participants reported other improvements related to an increased frequency of contact with the healthy parent, and an increased sense of closeness with that parent. It is noted that positive changes in the relationship between the healthy parent and child were not universal, with evidence to suggest that strain and resentment might increase. Specifically, one participant expressed anger and resentment toward her father in relation to his care for his wife. As she put it, "he wasn't giving his best to Mum," and without her mother to "act as a buffer," the tension had continued beyond her death. Another participant echoed this notion of the healthy parent not doing what the adult child perceived as right when he described his disapproval of his father's behavior toward his mother, and that consequently "I don't make the same effort as I would have done before for him." It therefore seemed evident to us that changes in the relational dynamics between a healthy parent and a child, in response to parental cancer, might occur in both positive and negative ways.

Participants also reported increases in sibling relationships, because the experience of parental cancer often increased contact and opened communication between them. One participant reflected, "My relationship with my siblings is a lot stronger. It was never fought but it wasn't particularly close, and we did a lot of sitting during Mum's illness and then after." For some participants, however, it was noted that changes in relationships with other family members were at times problematic, and marked by increased conflict and resentment, especially in relation to care issues. For example, one participant felt that her brother and sisters should have been more involved with their mother's care. Their refusal to help had placed her in the role of primary carer, a role that she adopted to support her mother, but which she did not enjoy, as evidenced by her statement:

"I don't like it [being the main carer]. I don't like it, and I have said to [my siblings], "Look, I'm the baby, you're all older," . . . but they just don't help. They are now considering that she is better, but when she was in her worst stages none of them came near her. They thought it would be best if they just stayed away, 'cause I'm in there, but I didn't go in there blaring and say, 'I'm going to do it all.'"

**Altered Life Priorities**

The participants used a variety of phrases to express how parental cancer had, in some way, changed their outlook on life. Participants used expressions such as "I don't put things off"; "Live for the day,""I don't care what people say"; and "I don't take life so seriously"—sentiments that were cited as being positive changes that had arisen. One participant, who experienced having both parents with cancer, had become quite philosophical, and recognized the illness as a learning opportunity. She commented,

"If anything is sent to you like an illness like that in the family, that you can learn so much from it. You can either be very negative about it and see the worst side of it, or you can see the better side and what you have learnt from it."

Some participants had made concrete changes to their career paths, or altered the pattern of their work. The most significant change was observed in one participant who, after the loss of her father, decided to become a "pioneer" and fulfill a long-held dream to develop a rural property. In doing so, both she and her husband left secure employment. When asked to reflect on that time, however, she did not mention the loss of career, but rather reflected that "it was a great thing because we created something together as a family that we had and that was new." Notably, the two men in the study made changes to their work patterns, with one turning down employment opportunities to allow him to continue to care for his father, and the second stated, "I. . . don't work with the same rabid ferocity that I used to." The participants reported other changes to their outlook on life, which included a greater willingness to try new experiences, travel, and a general slowing of the pace of their lives. From these recollections, it was clear that parental cancer might motivate some individuals to reassess both their vocational and personal goals, and to realign their behaviors to a path that better suited their new insights into life.

**Personal Development**

Participants reported some beneficial changes in their views of self; however, this was to a substantially lesser degree (i.e., mentioned less frequently, with less emphasis placed on such changes, or less detail provided by the
participants). The most commonly discussed changes were a sense of increased compassion (e.g., “I think probably a much greater awareness of what it means to other people when someone dies”), emotional maturity (e.g., “I don’t want to think about growing up, and it just made me”), and the development of experiential wisdom (e.g., “[Now] I always see life as a huge learning curve”).

The participants’ contact with the medical system was increased by having a parent with cancer. Some participants reported that this presented great challenges for them, especially in the perceived need to advocate for better care. Consequently, some participants felt that they developed increased confidence and assertiveness to deal with a system which they perceived had failed in its duty of care. One participant described it in this way:

“I think in some ways I have a greater confidence in some things... confidence in not letting a health system run itself so to speak, in being able to say, “Well hang on a minute. What is this? Why are you doing this?” And challenging things, and that challenge may simply mean getting more information and that is all I need, or having the care better, better quality of care.”

The participant accounts also provided evidence suggesting that parental cancer increased their awareness of their own cancer risk, and several participants mentioned changes to their health behaviors. Specifically, participants described being more aware of preventive measures for sun exposure (e.g., hat, sunscreen), the need for regular medical checks, dietary changes, and changes to their medication usage. The participants also displayed some understanding of how lifestyle factors might have contributed to the development of their parent’s cancer (i.e., stress, drinking, and smoking). Typically, participants also identified similar behaviors in themselves, but reported that they had made no attempt to alter those behaviors. For example, one participant perceived that her parent developed pancreatic cancer “because he was too dependent on alcohol” and “he drank like a fish.” She later reported that she had questioned whether she had similar tendencies, and whether that meant that she would develop pancreatic cancer, but confessed, “It doesn’t stop me from having wine, but it makes you wonder.”

Discussion

In conducting this study, we sought to gain insight into the types of benefits that adults reported from the experience of having a parent with cancer. Four distinct benefit themes emerged, including positive changes in the relationship with a sick parent, an increased valuing of the family, altered life priorities, and personal development. However, we found that the emergence of such benefits cannot fully be examined and appreciated unless one understands the emotional turmoil that accompanied this experience. The stories that were shared suggested that although some positive outcomes had emerged, it remained a time of intense and emotional upheaval, and change. The stories recounted by the participants provided great insight into both the positive and negative aspects of what it was like to live through parental cancer.

The narratives detailed how parental cancer triggered a range of emotions that had the potential to overwhelm, and were considered traumatic. The language used by some participants indicated that they had evaluated the impact of their parent’s illness against other significant events in their lives, and often rated it among the most stressful. There is some discussion in the cancer literature regarding whether life-threatening illnesses such as cancer constitute trauma for family members. The Diagnostic and Statistical Manual of Mental Disorders (American Psychological Association, 2000) now includes learning about the threat of death in a family member as a potential trigger of PTSD. Research evidence also supports the notion that PTSD can arise in family members of cancer patients. Smith, Redd, et al. (1999) reviewed research that examined PTSD in cancer, and found that cases of PTSD were present in the parents of childhood cancer patients, which supports the suggestion that, in some circumstances, the stress of having a family member with cancer might give rise to clinical PTSD. Lindberg and Wellisch (2004) have suggested that the risk of PTSD might be increased for family members who perceive themselves to be at an increased risk of cancer because of a possible genetic heritability (e.g., breast cancer). Although we did not examine the clinical symptoms of PTSD in the present study, the language used by the participants provided some insight into the magnitude of the impact that this experience had on them. Furthermore, the reported emotional upheaval, and the studies cited above, strengthen the argument that we must increase our understanding of how parental cancer impacts on adult children to ensure that we meet both the short- and long-term adjustment needs of all family members.

Another important pattern that emerged from the data was that those participants who appeared to have experienced a high degree of emotional turmoil and disruption to their regular routine also reported a higher level of perceived benefits. For example, one participant described a strong emotional reaction to his father’s diagnosis, accompanied by a high degree of disruption, because he struggled to balance his care responsibilities with his work commitments. This participant also identified more areas of perceived benefit than any other participant. In contrast, another participant, who reported that her life had not changed that much because of her father’s cancer, reported
minimal beneficial change. This pattern supports the under-lying premise of theories proposing that growth is an outcome of negative life events (see Janoff-Bulman, 1992; Tedeschi & Calhoun, 1995, 2004). Indeed, such theories argue that an event must be stressful enough to disrupt one’s psychological equilibriums, and it is through the struggle to reestablish core psychological assumptions that positive change occurs. The data we obtained in this study seemed to support this theoretical contention; however, firm conclusions cannot be drawn because of the nature of the data. We suggest that additional research examining this pattern should be conducted.

In terms of the types of benefits reported, our interpreta-tion of the data suggests that they are similar to the types of benefits reported by cancer patients and their spouses. For example, Thornton’s (2002) framework of the benefits for cancer patients and their spouses classified these benefits into three areas: benefits associated with interpersonal relationships, life perspective, and the self. The adult children in this study clearly reported similar categories of benefits as those found by Thornton. Furthermore, there are some similarities in the types of benefits reported in this study and in the research by Kim et al. (2007), because the authors of both studies have reported bene-fits in the areas of appreciation, family, empathy, and repre-sentation.

Thornton (2002) also investigated the frequency of ben-efts within each category, and found that for the majority of people, cancer positively transforms familial relationships. A similar result was obtained in the present study, with the themes of transformed relationship with the sick parent and an increased emphasis on the family strongly represented in the data. Similarly, Dumont, Dumont, and Mongeau (2008) reported that the relational context in family caregiving situations has the potential to enhance the existing ties between family members. Okuy (2005) and Tarkan (1999) also presented cases in which enhanced parental relationships were clearly evident, adding additional support to the contention that parental cancer can have a positive impact on the individual’s family relationships. Although positive changes did arise in the measure study, it is acknowledged that some participants also reported negative changes in their relationships with their siblings and the healthy parent. Although negative changes were mentioned less frequently, they are consistent with the findings of Carbow, Legro, Blaker, Wingard, and Somerfield (1993), who found that approximately 8% of their sample of bone marrow transplant patients reported declines in their familial relationships.

Although we acknowledge the similarities between the data presented in this study and the review by Thornton (2003), there are also notable differences. For example, Thornton identified benefits relating to self, such as taking time for oneself and higher levels of satisfaction with life accomplishments; these benefits are notably absent from the present data. There are several possible explanations as to why minimal benefit finding emerged in the area of personal development. It is possible that because the illness was in another person, the adult child’s attention was directed externally toward others, and therefore introspective self-reflection was reduced. Another possible expla-nation is that parental cancer added to the workload of the child and, consequently, he or she was squeezed between parental responsibilities, cancer, and his or her own family. Consequently, they were “time-poor” and therefore did not have the opportunity to engage in activities that might have enhanced their personal development. Alternatively, the finding of different benefits associated with the self in the present study might be a by-product of the small sample size, and therefore an investigation with a larger sample is warranted.

Limitations
This study is to some degree limited by the characteristics of the sample and the methodology employed. To be eligible for participation, individuals needed to have had a parent with cancer at some point in their adult lives (i.e., post age 18). This gives rise to two problems: first, the period between the experience and the interview, and second, the broad range of cancer types that were discussed. The length of time between the experience of parental cancer and the interview varied greatly, with the longest period being 25 years and the shortest just 12 months. It might be argued that the detail of recall can be affected with the passage of time, and the types of positive changes discussed might have been influenced by other life events in the interim period. Therefore, it is suggested that future studies of this nature provide some time frame in the eligibility criteria (e.g., within 2 years of diagnosis).

The second limitation with regard to the sample relates to the range of cancers present. In planning this study, we decided not to limit participation to a specific cancer type in an attempt to address the imbalance in the existing literature, which predominantly focuses on breast cancer. The range of cancer types, combined with the small sample size, might have reduced the possibility of discovering important insights into the experience of parental cancer. For instance, it is conceivable that parental brain cancer, with the associated cognitive changes, is more traumatic than other cancer types, and that this might give rise to different patterns of perceived benefits. An investigation with larger samples into particular cancer types might provide a fruitful avenue for future investigation.

A third limitation is the relatively small, heterogeneous sample. Data saturation was achieved in this study; however, the inclusion of other varied participants (e.g., a greater
number of men, and people of alternate races and cultures) would offer the potential of finding additional themes missing from the data presented. However, Smith and Osborn (2003) argued that IPA studies typically involve small samples because of the volume of data generated and the intensive analysis undertaken. Indeed, Smith and Osborn proposed that a sample size of 5 to 6 is reasonable for interpretative phenomenological studies, and therefore the current sample was large by such standards.

We aimed to examine the type of benefits arising from parental cancer and, as such, the participants were interviewed once. Because of the cross-sectional methodology employed, it is unknown whether the type and level of benefit reported changed over time, both during the illness experience and after successful treatment or the death of the parent. This is an area that potentially deserves attention, especially if the ability to derive benefit from parental cancer assists the individual to find meaning in the losses he or she experienced. However, Funk and Sigurdh (2009) argued that drawing conclusions about the family caregiving experience from interview data alone is fraught with problems, because the data represents both the individuals’ description of the experience and their coping efforts. It is argued that interview data be supplemented with longitudinal methods and observational techniques to enhance the depth of understanding (Funk & Sigurdh). The inclusion of such methodological enhancements would allow for more detailed examination of the phenomenon of finding benefits within the adult child cohort, and therefore should be considered in the design of future research.

Implications for Practice
The findings we have presented indicate that the experience of parental cancer was emotionally distressing for adult children, and therefore programs to support these family members are essential. An important finding was that adult children were able to derive range of benefits from the experience of parental cancer, but that this positive growth seemed to go hand in hand with the experience of distress and disruption. This finding needs to be acknowledged by those who have contact with the adult children of cancer patients, and it should not be assumed that just because they have been able to “see the bright side” of the situation, they do not require support. Indeed, the suggestion that greater benefits arise from greater distress and disruption suggests that additional attention and support might be needed for such individuals.

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Leveque and Maybery


**Bios**

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Appendix B: Author Reflection

As the daughter of a cancer survivor, I agonised over whether to conduct research in this field for fear that my experience would limit my objectivity. However, despite my desire to stay away from this disease, I found that I had a question to be answered and, while I looked for niches within psychological research into other diseases (e.g., diabetes), I found that no topic held my interest as much as the question I had about cancer.

The question is – is it possible to derive benefits from the experience of parental cancer? However, when I started reviewing the literature in this area, I found that there was very little and, consequently, there was great ambiguity surrounding what it is like to have a parent with cancer, when one is an adult. So, while I was still very attracted to the investigation of whether positive benefits were possible, I was also interested in gaining further insight into what this experience is generally like.

While there are some differences between myself and the people I have spoken with on this topic (mainly I was an adolescent and they are adults, therefore we were facing different developmental stages, when our parents were diagnosed), I still bring to this investigation a number of assumptions and beliefs that I need to be aware of and manage, so that they do not cloud my judgement, influence my interactions with both the participants and the data they provide, or sabotage my analysis of the data. Consequently, I write this reflection to lay these beliefs out in front of me to ensure that I am aware of them, and can try to monitor how they influence my interpretation of the data.

As a result of my experience of parental cancer, I believe:

1. Parental cancer has the potential to transform your life. I strongly attribute several changes that arose during this period directly to my mother’s cancer. Consequently, I must be wary that I do not assume that all people will be transformed by this; I must not see change in others, where it simply is not.
2. Positive changes can occur. Several of the changes that arose for me I view as very positive. For example, I was 16 when my mother was diagnosed, and at the heights of teenage rebellion. Her diagnosis put an end to that, as I had to take on responsibilities around the home, and look after aspects of her care. I often see this as her cancer making me grow up, before I had a chance to go down a potentially dangerous path. The implications of this assumption for my study are that I may want to see the good in all changes that arise, and I must not evaluate people’s situation in the light of my own views. If people are reporting a change to me, I must assess whether this is a positive or a negative change, based on their perspective rather than my own.

3. Cancer can mend relationships. My relationship with my sister improved greatly with my mother’s cancer, and we remain close today. While this may be true for me, parental cancer may actually strain the relationships within a family, and I must be cautious not to judge people, based on their perception of their family relationships.

4. My romanticism of cancer, the rose coloured glasses. My mother’s cancer was a long time ago for me (14 years) and, as such, I certainly have had time to reflect back upon it and evaluate it, extracting all the positive notions I can, while forgetting or downplaying the negative aspects. Often negative aspects that I do recall are held as badges of honour – gee wasn’t I strong to get through all that? Therefore, I must strive to be balanced in my investigation; while good things may arise, I must not search solely for that. To only focus on the positive aspects is to neglect the turmoil and suffering that children of cancer patients go through, and so only get a small insight into what it is truly like to experience parental cancer. Furthermore, such a narrow focus disrespects my participants by failing to acknowledge their full story, and restricts the contribution that I may be able to add to my field. I will also need to be mindful of the time frame – the years since my experience
have helped me forget the intensity of the experience, and I must not minimise the participants’ emotional experiences.

5. Families should care. This is a general belief that I have, which is not specific to cancer, but which will bear relevance on this research. I believe that when family members are sick, injured, or just getting too old to look after themselves, that the family should provide care for its members. It is my opinion that such care should not have to be asked for, it should be given freely. I do not perceive providing such care as a burden or a sacrifice, and I think it should be unconditional. This belief has arisen from seeing my grandparents care for elderly and disabled people during my childhood, and the care that I provided to my mother, when she needed it. I acknowledge that this is a very simplistic view, which fails to recognise the great complexity involved in caring for family members when they are ill. It may be that some people would love to care for ill family members, but practically it is impossible, or they do not have the skills required for such a task. I will need to be especially careful that I do not pass judgement on my participants, when they talk of such issues. Furthermore, I will need to take care in the data analysis that I do not interpret such passages in a manner that matches my beliefs. I must open myself up to the plethora of other opinions that exist on this topic, and respond to them unemotionally.

6. People don’t talk about cancer. Cancer in my family was lived, but not spoken about. In fact, it was 10 years after my mother’s illness, before we openly discussed what she had been through, and how it had affected her. When talking to my participants, I must not assume that they have similar ‘policies’ of disclosure. Instead, I need to be open-minded about a range of communication possibilities. I must also take additional care that, if someone mentions that they did not talk within their family about what was going on, that I do not assume that I know what this was like, and that the consequences of this silence are the same as the consequences were for me.
7. People survive cancer. I am very fortunate and my mother is still with us today, despite her case being very severe and potentially fatal. As a result of her survival, I do not believe that cancer is a death sentence. However, I am aware that, for others, the ‘big C’ is synonymous with death. It is very important that I acknowledge this belief, as I will be talking to people who have lost their parent, or who live in fear of losing their parent, and so I must respect their beliefs and situation, and not dismiss their fear and concerns. To do so would be to be completely insensitive to their experience, to miss an essential component of what they are going through, and it would belittle their emotional responses. I must also be open to exploring their fear, and how this impacts on their life.

From the list above, it is evident that I hold many assumptions and beliefs on the topic of parental cancer. I have written this list, whilst mulling the topic over in my head for several days, and so I think that what is written in fairly complete. However, I do also acknowledge that, as I proceed with this process and begin my data analysis, further assumptions and presuppositions may arise, and I need to watch out for them, and add them to my list as I proceed.

Janelle Levesque
22/02/07
Appendix C: Reflective Journal Extracts

27 February 2007 - First Reading of ‘James’ Interview

Thoughts during the analysis:

- In a sense, there are two stories present – the patient and the adult child. This, however, may just be very prominent in the initial sections of the transcript, when the participant presented lots of medical information to provide the context.
- There is a sense of desire to stay close to his dad. What is driving this? Concern? Fear? Obligation? Suspecting the worst?
- Bargaining – at some points I feel as though James is trying to ‘buy’ a good outcome. If I am a good son ... If I support this cause ... If I provide a grandchild ... [can my dad be saved?] What is the motivation behind this? Is he truly altruistic or is he needing to do it to feel like he has fulfilled an obligation? Or neither?
- Is James idealising/romanticising the notion of his Dad? Is he presenting me with a “Super Dad?” What is the significance of this for James?
- There is the sense that James is putting his life on hold until his Dad is better.
- Does being healthy = getting medical advice or checkups? There is no mention of lifestyle factors for James himself.
- There is a feel that, at various points in the interview, he has wandered into emotionally sensitive areas, and then pulls back to safer topics.

During the next read through:

- Look for emotional content
- Look for role strain – the concept emerges and is noted on p. 16, but is it present in earlier sections?

Personal reflection:

- I could feel myself ‘lift-up,’ when a positive aspect was presented. Take care to avoid bias, think about body language/facial expression, and make sure you probe on negative dimensions, as well as the positive.
- Reflect on your research question – at various points, there is a sense of confusion in my reaction to the text. Is the question “are there
benefits/positive by-products of having a parent with cancer?” OR is it “what is the experience of parental cancer like?” OR are the two linked (i.e. do I need to understand the experience to make sense of the positive?)

28 February 2007 – Second Reading of ‘James’ Interview

Thoughts during the analysis:

- Still picking up this idea of needing to be there/be near.
- Is there evidence of a changed perception of the parent – so before the cancer, the parent was viewed in one way, the cancer experience changes the way the child views their parent, probably softens their view, makes them more forgiving of past conflicts/wrongs? Is that a broad theme with various distinctive sub-themes within?
- Topics that seem to be jumping off the page for me today are: education as a key to coping (i.e. finding out as much as possible about the disease), and control – through getting education, and through taking control of the situation where possible (i.e. controlling family visits).
- Is he hiding an internal tension – is he engaging in care activities and putting on the positive, humble image, when really there are negative aspects as well. Does he deny the negative, and is that a part of how he copes? What is making me think this? On next read-through, what phrases are bringing forth this impression? Check with audio for tone or other vocal features that might confirm or refute this sense.

Personal reflection:

- In some ways, I feel like I doubt James’ sincerity, feeling like there is more to his desire to be near his Dad and care for him? Why? This aligns with some of my personal assumptions (i.e., that family should provide care), so why am I seeing something that may not be there? Am I trying too hard to avoid interference from personal assumptions?
Appendix D: Study One Ethics Approval

20 September 2006

Ms Janelle Levesque
119 Undara Drive
WAGGA WAGGA, NSW 2650

Dear Ms Levesque,

Thank you for the additional information forwarded in response to a request from the Ethics in Human Research Committee.

The Committee has now approved your proposal entitled “The Experience of Parental Cancer”. The protocol number issued with respect to the project is 2006/243. Please be sure to quote this number when responding to any request made by the Committee.

You must notify the Committee immediately should your research differ in any way from that proposed.

You are also required to complete a Progress Report form, which can be downloaded from www.csu.edu.au/research/forms/eohrc_annrep.doc, and return it on completion of your research or by 20/09/2007 if your research has not been completed by that date.

Please don’t hesitate to contact the Executive Officer telephone (02) 6338 4628 or email ethics@csu.edu.au if you have any enquiries about this matter.

Yours sincerely,

Julie Hicks
Executive Officer
Ethics in Human Research Committee

Cc Mr Beryl Maybery Dr Kent Patrick
Appendix E: Study One Interview Schedule

Experiencing parental cancer
- Tell me about your parent’s cancer.
  - May prompt - What was this experience like for you? How big an impact would you say this has had on your life?
- What are some of the changes in your life that have emerged from your experience with your mum/dad’s cancer?
  - Clarify with participant whether they view each change as a positive or negative aspect of the experience.

Family relationships
- Tell me about your relationship with your parent, both before the cancer and what it is like now?
- Can you describe how you believe parental cancer has changed your family, if at all?
  - May prompt - Your relationship with your siblings? Your other parent? Family interactions?

Coping
- How did you adjust to your parent’s cancer?
  - May prompt – at diagnosis, during treatment, now?

Cancer-Related/Adjustment-Related Cognitions
- What are some of the cancer-related thoughts or beliefs you used to help you deal with your parent’s cancer?
- Cancer is often described by patients as a time of self-reflection and personal growth. Do you believe that you have undergone similar growth or reflection? Can you tell me a bit about that?
- Often cancer patients search for meaning in their illness, either trying to explain why they got cancer, or how it is significant in their lives. Have you gone through a similar process?
  - Can you tell me about this?
  - Do you believe this search for meaning has helped you adjust to your parent’s illness?
- To what extent did you feel that you could control any aspects of this experience? How did this influence your handling of your parent’s illness?

Personal Health Behaviours
- Do you think that your parent’s diagnosis of cancer has altered the way you look at your own health? Can you tell me a bit about this?
- What behaviours, if any, do you engage in to reduce your chance of getting cancer?

Conclusion
- Are there any other important things about this experiences that we have not covered today?
Appendix F: Example of a Worked Transcript

In the following transcript, the notes on the left hand side represent responses to the text made during the initial and subsequent readings of the transcript. The notes on the right hand side are the master theme titles, which were developed for that specific transcript.

<table>
<thead>
<tr>
<th>Penny Master Themes</th>
<th>My Health</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sibling relationships</strong></td>
<td><strong>Hyper-vigilance</strong></td>
</tr>
<tr>
<td>Improved sibling relationships</td>
<td>Health plan for recovery</td>
</tr>
<tr>
<td>Relying on each other</td>
<td>The inevitability of illness</td>
</tr>
<tr>
<td>Letting go of past irritants</td>
<td></td>
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<tr>
<td><strong>Mother-Daughter Connection</strong></td>
<td><strong>Coping</strong></td>
</tr>
<tr>
<td>Special conversations</td>
<td>People – professionals</td>
</tr>
<tr>
<td>Mum’s protector</td>
<td>People – informal support</td>
</tr>
<tr>
<td>Keeping the connection</td>
<td>Cognitive transitions</td>
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<tr>
<td>Honouring Mum</td>
<td>A point of reference, benchmark, life</td>
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<td></td>
<td>perspective</td>
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<td></td>
<td>Just vs. unjust loss</td>
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<tr>
<td><strong>Dealing with the Medical System</strong></td>
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<td>Quality of care</td>
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<td>Challenging the medical system</td>
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<td>Being acknowledged by the system</td>
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I: Well first of all can you just tell me about your mum’s cancer?

P: Yep, well she got diagnosed around this time of year actually, about 4 years ago and she had a cordoma in the vertebrae in her neck.

I: yep

P: and it was one that they wanted to be able to take out completely because it had spores or something like that I don’t know all the details but it had grown to such an extent because she kind of ignored all the symptoms she had for a while and it had gone into the two vertebra above and below, well the one above and below, and had circled around one of the arteries in her neck.

I: yep

P: yeah so that was what it was, and it involved umm taking it out and doing a taking out bone from her hip and replacing it and they ended up trying to do a artery transplant, well took one out of her leg, to see if it would take so she had within a week she had a fairly major operation trying to do the artery thing and then another one to try and remove the cordoma.
I: How did the artery transplant go because I have never heard of that?

P: It didn’t hold, she had, she was very overweight, she had type 2 diabetes, umm she had sleep apnoea as well so there were those sort of issues for her as well, and she had umm, cellulitis in her legs so there was some risk in taking out the artery thing as well and that ended up getting infected and so a couple of months later she was back in with that, so that unfortunately didn’t hold but the whole idea of it sounded good

I: yeah, wow I was listening going wow that is so ambitious

P: (laughs) I know, it was extraordinary and they did try it but she, with that operation she was facing risk of stroke as well as death, so she was facing that and then when it came to the actual time to doing the, taking the cordoma out there was risk of death and stroke and complete paralysis and I think her greatest fear was the paralysis really

I: yep

P: yeah
I: What was this experience like for you?

P: Umm from whoa to go from her being diagnosed through to her
dying about 6 or 7 seven months later it was probably the most
difficult thing that I have ever had to go through, it was also for me
something that, I mean I knew it was something that would be
difficult but I also knew I had to do the best I could, that is what I
wanted to do the best I could with mum and umm I guess fight for
her in some ways. I mean the care that she got at
LOCATION Hospital was great, the care that she got in other
hospitals wasn’t and we probably didn’t have to fight very hard for
the care at LOCATION because she spent about 4 weeks in intensive
care there. But it was all so incredibly draining, it was a
rollercoaster, and there was also for me at different times a sense
of when will it end, I wish it would end either way in some ways,
mostly with her getting better of course

I: yes

P: umm, and I was very distracted so I found it really hard to work
family enough, but work was also really supportive and you know
my partner was supportive as well. We have three children so
my brother and my sister and there’s my father as well but us three
kids were very supportive of each other as well so that all made a
difference.
I: Yeah. Overall how big an impact would you say this had on your life?

P: It has been hard to actually say, I mean it was been the biggest thing. I mean there have been things that have had a big impact and may have been a long-term impact but for me this was just such an intense period.

I: yep

P: and you know three and a half years later from when she died I still think that there are reverberations in some ways, you know especially around Christmas time, it is also the anniversary of when she did get diagnosed.

I: yep

P: and umm it was also tied up with both my grandmothers dying within 9 months of mum dying, both before yep but there were those as well, although they are different because they were both elderly.

I: yeah
P: umm but it was still like suddenly all the mother figures were
gone and that was a really big impact as well

I: it would have been

P: yeah, yeah, yeah

I: What are some of the changes in your life that you think arose
from this?

P: Umm Oh god there are all sorts I guess. I think in some ways I
have a greater confidence in some things because of umm
confidence in not letting a health system run itself so to speak, in
being able to say well hang on a minute what is this? Why are you
doing this? And challenging things, and that challenge may simply
mean getting more information and that is all I need or

I: yep

P: having the care better, better quality of care. So we ended up
putting in a complaint to the complaints commission about one of
the hospitals and so that was all sort of umm, a whole other thing
as well, so in that sense I think yes you know I have greater
confidence in doing that stuff
P: Other changes, umm thinking about death a lot more. You know you can always go around thinking that you are going to die one day but mum was only 62 which to me was too young.

I: yeah

P: and umm so I think about that a lot more, if I get a pain in my neck I think about it (laughs)

I: yep

P: and other, you know if I get another pain I will think about it, although I don’t necessarily act on it. Umm I think other changes, I think probably a much greater awareness for what it means to other people when someone dies, you know I have had friends whose sister has died, whose parents have died, different friend whose parents have died.

I: yep

P: and stuff and I sort of gave some sympathy about it but didn’t really get it and umm so it has given me a greater awareness of that. And also just a greater awareness of how someone’s response
to death is just, and to the cure and the illness as well is just so individual.

P: and I was quite surprised at myself when after mum died, my workplace was very sympathetic and supportive, but people would say things and I would get so angry and I realised eventually that it was about, well it, sometimes it didn’t matter what anyone said, they could have good intentions but I would just be really pissed off so I had to reign myself in a bit and sometimes I can still get that if I am in a situation where I am thinking about it or talking about it or whatever. Umm and there have been a lot of changes in our family because mum was the one who held us all together and we’ve had to, I still don’t think we have found our way of being together without her even though I feel that we should have after 3 and a half years, but umm, my relationship with my siblings was a lot stronger, it was never umm fraught but it wasn’t particularly close and we did a lot of talking during mum’s illness and then

I: yeah

P: as well so that has changed quite a lot. Yeah

rls: relationship.
I: Overall, what would you say were the most difficult things to handle?

P: My father (laughs)

I: I hear that one a lot

P: I’m sure you do, umm well he was probably one of the most difficult, in some ways the not understanding the system, but it wasn’t too bad because I consider myself fairly assertive, my sister is a social worker and my brother is a doctor so in some ways I think we had it easy.

I: yeah

P: we had someone who could interpret for a start

I: yes

P: but it still that unknown stuff I found very difficult. My feelings of wanting to run away were difficult and at times when Mum was in intensive care they would send us out because they would have received to do things and at times I would be relieved even though a part of me still wanted to stay there. Umm so all of that was difficult.

There (pause) umm waiting for the operation to be over was
I: mmhmm

P: it was a 15 hour operation and that, that was hell.

I: That is a lot of time to spend thinking

P: yes, yes it is and waiting in that bloody waiting room with uncomfortable chairs, and we got to something like 8 o'clock at night and she had gone into the operation at 9, it must have been about 6 or 7 o'clock and someone came up and said oh they’ve now taken the tumour out so they hadn’t even done everything else and we thought by then that it would be all done, and so we are sort of dealing with it thinking oh fuck we have to go through more, and we have to wait, and is she going to be alright this long under anaesthetic and stuff. And there were other people there who had gone out and gone pizza and celebrating because the person they were there for had woken up, or was getting out of ICU or whatever it was and that was really, I wanted to tell them to shut up, but of course they also wanted to celebrate, but then I think they realised at some point that we were upset and they took the stuff outside which was quite nice

I: mmm
P: but it, I mean what was difficult about that and at other times was managing other people, either going through distressing stuff or the good stuff and just managing other people and my reaction to them.

I: yep.

P: and of course because we were around for so long we got to know other people.

I: yep.

P: as well so I was acutely aware of when we had good news and they didn’t.

I: mmm.

P: so all of that sort of stuff was a little bit difficult. And then, umm probably the most difficult part of it was, well another difficult part was that mum went into a deep depression after cancer-related losses.

I: yep.

P: she got out and it didn’t matter to her that we could explain that...
It was completely normal, it was just really hard to, to keep her focused and positive which I don't think we did but also at that stage she was home, or in rehab and on her way home and we started going back to our lives so we weren't around as much so there was guilt mixed in with trying to keep her positive and get on with our lives, even though she is a part of it of course. But the most difficult bit was, she had had a fall when she was home and hit her head and she had a bleed in her brain so from that point on, that was the week after Mother’s Day I think, through to early July when she died she was never herself due to the damage that build up of blood, so it was dealing with that and dealing with her being someone else for a while. She had always been really smart and good with words and umm she couldn’t communicate properly, she couldn’t get the right words and that was really distressing for her and for us. And then she went to [LOCATION] hospital on a way to rehab and they weren’t really sure whether she was suitable for rehab because she was still not with it entirely and wanted to get out of bed and out of chairs and she fell out of bed and fell flat on her face and broke her nose and had a bleed in the brain again and died two weeks later. So as I keep talking I kind of think that was the worst and then no the next things the worst (laughs). Umm so that was really hard and knowing what to do about that, and I think they dealt with it really badly and so that is where the complaint lay and then the relief that she got transferred to [LOCATION] because we figured she would be well looked after there.
P: and then the hardest thing with that was making the decision not to continue on with treatment. She had had the pneumonia you get when you ingest, when you breathe in food.

I: yep

P: and she wasn't with it, and so this was about 2 weeks after, maybe a week after she fell in the hospital I can't remember exactly, they did have an operation where they had eased the build up in her brain of the blood and stuff, and umm so she had a brief lucid moment after the fall before she went into intensive care again and she said then that she didn't think she would make it.

She and I had had a really long talk when her mother died, I took her to the nursing home to see her mother as this was three months earlier and mum talked about not wanting to be in a nursing home, not wanting to be paralysed, she had a plan for euthanasia and so we had talked about all that and she was clear about what she wanted and I was clear about what I could do which did not involve killing her obviously, because I thought that was what she was asking and I was like I cannot do that (giggles) umm so I had all of that information because I had had that conversation with her and others hadn't, I mean I just had the opportunity really, umm so
then the doctors were saying we don't think that there is anything else we can do so then that decision to take her off the respirator, it's not a respirator is it when they extubate

I: yeah, it's the tube down the throat

P: yeah but she wouldn't stop breathing without it, but would be difficult for her. So they took that out and we didn't actually tell her that that was going to happen

I: yeah

P: but we had made this decision because we didn't know how lucid she was, but she had always been someone who wanted to know exactly, I mean yeah, so that was on a Friday, on the Saturday they took her into a room on her own and we just moved in basically so we were with her the whole time and on the Saturday night she just wanted to know what was going on and I ended up telling her and that was probably the most difficult thing, saying this is what's happening and this is the decision and I could sort of draw on the conversation we had had and I don't know if she remembered that at all but after telling her she went very calm and shut her eyes so I think I did the right thing

I: yeah
P: but it was just, the most hardest thing I have ever done.

I: It must have been very heartbreaking.

P: It was, it was, but it was also something I had to do.

I: I bet you wish either your sister or your brother had had that conversation with her.

P: I don't know, yes and no and in some ways and this is in retrospect not at the time the conversation that we had over my grandmother's body basically and before she went in for the operation to take the cordoma out, you know I had asked her if she did die if there was anything she wanted done, if there was anyone she wanted contacted and things like that.

I: yep.

P: and umm there was someone that she wanted contacted and I did that anyway, it was a friend that she had lost touch with and the friend told me after she died that mum had said to her that she felt that I was the only one that she could have those conversations with, so it just seemed like we had had those conversations so it was just my job to tell her that stuff, and I don't know I might be.
making that stuff up just to make myself feel better but umm yeah that is what happened and that is the way it happened. So yeah, that is all the illness stuff that was the hardest and then just some of the hard stuff was, getting on with life is the wrong thing, but just starting to move away from it and that still comes up occasionally, like this will be fourth Christmas without her and it's like that's too many, it shouldn't be that far along and it is hard to deal with that day to day sometimes. Yeah. Does that answer all your question, I feel like I've rambled on.

I: No that's great. The other side of the coin is has there been anything positive to come out of this?

P: Quite a lot in some ways. Umm there was really umm nice interactions with people, it is one of those times I think illness in whoever in our family and in other families brings out the best and the worst and you are sort of in this space with other people going through the worst things as well and there would just be all sorts of odd little interactions that just sort of reminded me that a lot of people are good people

I: Yeah

P: And at the time, I worked for a counselling unit working with traumatic... so what I talked about everyday was the bad
staff and the torture so it was nice that what was within what is

savouring moment

finding comfort

interactions, those positives

I: mmm

P: I mean there was one guy who umm had come in when mum

was in intensive care the first time she fell, so the second round

and he had been in Sydney for about 3 days or something and his

family was in England and he had been in this really bad car

accident and they had had to take away part of his skull, and so he

survived and the second time mum fell and she was in intensive

care his parents were there and umm he wasn’t in intensive care

anymore but he was in the ward that mum moved to and mum was

going to die and I saw this kid sitting up with this helmet on his

head and his parents and stuff and then he wasn’t there and I

approached the father and asked if he was his son and that I was

around when he came in and its really nice to see him and blah

blah and he asked about mum and I said we were letting her go,

that she was going to die

I: yeah

P: and he just took my hand and squeezed it and it was just nice,

recognising the compassion of others.

like it didn’t have to be anything else it was just an

valuing people.
acknowledgement of the pain we had both gone through and umm

yeah mothers do die and sons shouldn’t so you know I think about

that stuff. There was also just seeing really good stuff, and some of

the staff came to mum’s funeral and they were people who had

connected with her on something other than a patient-nurse level

so that was nice

I: yeah

finding positives in unexpected places.

P: umm, and probably the funeral in some bizarre way was

positive, there were over 100 people there and we didn’t expect

that

I: Isn’t that lovely

P: I mean we did sort of expect it because we got a big chapel

because she had done a lot of volunteer stuff in the last 10 years

but it was just really nice to get up there to speak and just be

overwhelmed by how many people were there.

honouring mum.

I: yeah

P: and I guess the other one is having a better relationship with my

siblings, that that is a good thing as well.
I: Tell me a little bit more about that, like you have said that you are closer or better but what do those words mean to you?

P: yep, so umm (pause) we, dad’s an alcoholic, he is soberish now (laughs) although he has been taking other drugs which we didn’t know about but when we were kids he was a violent alcoholic so everything that is within a family with that and we, we were quite clear that we were aware at a time like this we were quite likely to fall into old habits of coping and we didn’t want to do that, we wanted to give mum the best we could but also support each other, so there were times, I think there were times, and I mean I can say this because I wasn’t aware of my own behaviour so much

I: yep

P: but I would see my sister doing the eldest sister stuff and it would get me narky but I would just stop myself and go I could either challenge her on it or let it go

I: yep

P: and most of the time just let her go and didn’t challenge her, although I may have stepped in with some things but umm, were as other times I would get narky and react, and there were other times where we could talk about that and not falling into the, so I think
that that sort of happened. But also my brother and I, it goes my
sister, brother, me, my brother and I have never particularly got on,
we fought a lot as kids and just don’t fight but we had been distant
and had a sense of not knowing each other, and he lives in
location and I am here so, you know, it was always civil but
that was about it really, we talked about all that, he and I were
sitting with mum and you know we had sort of turns overnight
sitting with her and he and I just sat with her and talked about that
stuff and about not knowing each other and about being fair with
each other about that and it always bothered mum that he and I
fought, or didn’t get on, or didn’t like each other

I: yeah

P: and umm she and her brother didn’t get on either whereas I just
always thought sometimes you don’t get on with people, you can’t
be forced into liking people, so afterwards I thought oh I don’t
know how conscious she was but it was probably a good thing that
on some level she heard all of that conversation. Yeah so they are
the sort of things that happened and since then have umm, you
know there are things happening in both of their lives, my nephew,
my sister’s son has a mental illness, he is getting voices and we are
not really sure what that means so she is dealing with that, my
brother’s marriage is breaking up and so I am sort of aware that
things are going well for me at the moment, so now I am realising

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that now it is my role to be a bit more stable and support them a bit and wanting to do that, being comfortable about doing that.

I: So with your brother you are still remaining in more contact?

P: yeah, and he will actually ring me for a chat which didn’t used to happen.

I: Umm what about your relationship with your mum both before her diagnosis and after, did you feel that your relationship with your mum changed?

P: Don’t know that it so much changed, I think our relationship was fairly close, I would ring her every few days and chat, umm but equally having done therapy was quite critical of her at times as well, now of course I regret and feel very guilty about that but I think it is also very normal. I think the only, it didn’t so much change but brought to the fore for all of us how protective we felt about her.

I: yeah

P: and that came out quite strongly so I don’t think it was so much a change just stronger.
I: And what about your relationship with your dad, do you think that has changed?

P: (laughs very loudly) I don’t think so much it has changed but again the reality of it is much more obvious. He didn’t cope very well with it at all and mum had said to us that she couldn’t look after him and we would have to do that and I don’t think we did a very good job on that, I don’t think we appreciated enough, umm what that meant.

I: umm

Resentment

Obligation, what mum needs me to do.

P: and also we didn’t want to have to and I don’t think we thought through that she needed it

I: yeah

regret
sadness
selfishness
unflexible father
anger/resentment
letting mum down

P: umm so it is one of the regrets that I have. And he wouldn’t stay in the hospital for longer than two hours, and we would try to do shifts and he wouldn’t accommodate that so umm, for me there has been quite a lot of resentment around that. But what we didn’t know was that umm he was also taking tablets that, so he wasn’t giving mum his best either

I: no, no
P: so we all have a lot of resentment about that, but then since she has died, he it wasn’t until last year that that stuff came out. We were trying to get him to do all sorts of stuff and trying to be supportive but umm, and thinking he is depressed but no he is taking tablets and drinking cough medicine and that sort of stuff.

I: yep

P: what we all realise, I say we because we have discussed it but certainly for me, is that mum was a buffer for us all.

I: yep

P: and now she has gone and I am actually one of the ones who will say what I think, so the others have held in stuff where as I’ve gone in boots and all so that has been difficult for him and for me really, and he has been in and out of rehab, well he was last year, umm and then what was your original question, just about the relationship?

I: Has your relationship changed?

P: Yeah I think it is that it is more fraught because mum is not there to act as the buffer.

I: Stark awareness of situation.
I: yeah, that makes a lot of sense.

P: yeah, yeah, and there is resentment from when I was a kid but there is a lot more now about how he has dealt with stuff, which may not be fair but there it is.

I: That’s life

P: It is, it is.

I: Umm thinking back, how did you cope, like what coping strategies or skills did you try to use, or for that matter not use?

P: Some stuff I was aware of how people respond to trauma so I figured that some of my responses were going to be like that so when some of my responses were that I could identify it and that gave me a bit of distance from what I was feeling.

I: yep

P: umm, I’d finished therapy, I went back and saw the same therapist, not regularly but a couple of times, umm sorry do you mean during mum’s illness or after?
I: Both really

P: When she was ill and in hospital I used whatever we could, so I would get towards the end both my aunts and their husbands came down and I would get them to try and deal with dad because I couldn’t

seeking help, allocating roles, trying to create buffer

I: yeah
P: There was a chaplain who was exceptionally good, like exceedingly good and I tried to get her to talk to dad, here can you give him some support, talk to him, umm so it was using what was there. Umm asking questions, recognising eventually, and it took me a little while, that the whole thing was a rollercoaster and that umm that eased the rollercoaster-ness of it, just recognising what it was. I talked a lot. I’m a bit of a talker and I talked to my friends about it and was very supportive. After mum died, after about six months I went to the bereavement care and spoke with a counsellor and I found that extraordinarily peaceful

social support

I: yeah

P: Umm, I spoke at mum’s funeral which I think was part of it, is part of coping, and since then have done things, like I had her birthday, I have the day off on her birthday and I’ve gone and done

honouring mum

honouring mum

honouring mum
something.

I: yep

P: So just, because we don’t have a grave for her, Dad has her ashes and umm so there is no place where she is but there are places that are significant for her, so on the anniversary of her death and her birthday I have often gone to those places that are significant to her. Umm and probably doing the complaint against [LOCATION] hospital was useful as well even though it was the most frustrating thing I have ever done. I ended up putting in a complaint about the Health Care Complaints Commission (laughs) that was probably the best thing I done, just to feel that we had done something about what I think was really bad care rather than just throw up your hands and say, oh that’s the way it is

I: yeah

Making a difference
Improving conditions, my suffering can benefit others.

I: mmm

P: yeah

I: What are some of the cancer related thoughts or beliefs that you
now bold?

P: What do you mean?

I: Well if someone says to you cancer what are some of the things that you think about?

P: Oh I still think of death, I think immediately of death, umm and I think of it as inevitable to some extent even though I know its not logically, umm and I guess I think of pain and suffering, I don’t see it as a positive thing and I guess it makes me highly anxious.

I: yeah

P: (laughs)

I: Cancer is sometimes described by patients as a time for self-reflection and personal growth. Do you feel that you went through a similar sort of time?

P: Yeah, yeah

I: What was some of the, well tell me a bit about that?
P: umm (pause) I think because it was the most, what I think of as the most painful thing I have been through, and if it is the most painful thing you have got to survive it and so

I: yeah

P: that's not really giving a proper answer (pause) I guess for me the most significant part, the thing I link it with was having those conversations with mum and talking about her death and I guess I consider that if you do something that you think is the hardest thing you have ever done then you do grow stronger from that, and for me those conversations were the hardest so I have a lot greater confidence in my strength and my resilience

I: yeah

P: that that is probably the most beneficial thing that has come out if it for me.

I: Do you think you have changed in any other way.

P: I don’t know, I think I am probably likely to be a little more adventurous, I’m not a very adventurous person

I: yes
P: But now I think there are things that I do want to do and you don't want to know when you will go, like I might be hit by a bus, you know, for everyone else in my family who has lived into their 90's who know I may live into my nineties, umm so that has changed for me. I haven't done a lot about it.

I: I was about to ask you so what have you done.

P: Not much, not much, but it can be simple things, like a friend of mine lives in the UK and had a baby and she, her wedding which I was bridesmaid for was in the UK about 4 weeks after Mum had died so we didn't know whether or not I would go and decided to go and at the time, because I wasn't in a really good space to celebrate.

I: yeah

P: Umm I remember thinking if she has a baby I'll go back, and it is not the time for me to be going overseas for a variety of reasons and I'm just thinking well bugger it I can go, I'll just go. And I don't like camping.

I: yep
P: and we, I went to the Northern Territory earlier in the year and stayed in motels and stuff, well not motels but cabins and things and I just thought oh fuck it, you see a lot more if you go camping so I just have to get over that and do it, so we haven’t got firm plans but we will be going.

I: yep

Little changes in our outlook, honesty, confidence benchmark. sensitivity

P: Yeah so it is just the little things like that and probably being a little bit more blunt and braver with people. Yeah again it comes back to that hard conversation. I had a conversation with the director of our workplace the other day and umm this is the bit you can’t mention but he is a bit patronising and there is a person there on a temporary position and we want to be able to keep her on and he was just saying you know take the emotion out of it, I know these are difficult conversations and rah rah rah, and then at some point he said oh this must be the first time that you have had to do this sort of conversation and I just thought I’ve had to tell my mother that she is going to die, this conversation is nothing but I didn’t say it (laughs). I wish I had.

I: I would have loved to see his face if you had.

P: (laughs) I have done things like that since mum has died where I have been a little too blunt and I think no I shouldn’t have said that.
but umm that was one of the times I think I wanted to. I think also because someone's mother had died and she was my direct boss

I: yep

P: and umm he had sort of gone off and given me this little lecture about what it means when someone's parent dies, and then he said, oh but of course neither of my parents have died (laughs) and I just thought you stupid man, let me tell you.

I: Have I got a story for you

P: yes, but I still tend to think that it is an overreaction on my part and I still tend to have those a little bit but that is alright.

I: Another thing that has come out of the literature on cancer patients is this idea that cancer patients themselves often go through what they call a search for meaning which has two parts to it, either they try to come up with a reason for why they got sick

P: mumhmm

I: Or they try to find the significance for it in their lives, so its like it's alright I have got this because it gives me a chance to do these things. Do you think you went through a similar thing?
P: I don't know if a search for meaning is quite right because umm finding meaning has always been important to me anyway and I don't think it is something that I have ever given up or started as such.

I: OK

P: and I was just aware that to move through it I had to find meaning of some sort because that is just a trauma response.

I: OK

P: I don't know that I did find meaning for it though, I think I have taken what I can out of like feeling stronger and resilient but I don't think I have found meaning with it yet and I don't know that I ever will.

I: I don't know if it is something that a lot of children, like adult children do get. Their lives are just so busy, as you said there were all these things that you just had to get on with as well as care for mum, I just think your lives are just a little bit too crammed for a full scale reflection that perhaps patients go through.

P: Yeah because it is not us that is going to die or potentially die.
I: yes it is that one step removed

P: and I think also the other step, and one of the things that does help me with the grief of it is that parents are meant to die, your parents do die and I have enough understanding that you know to evolve and keep living on the earth people have to die

I: That's just the way it is, that's the grand plan

P: I mean I'm not happy about it (laughs) and maybe that is where the meaning is, I don't know, I guess it is not so much finding meaning in mum having cancer but just taking what I could from the experience and trying to be better from it.

I: To what extent did you feel that you had some control over aspects of your mum's illness or her care?

P: Oh, very little.

I: How do you think that impacted on your experience?

P: Umm, it did vary at times depending on where we were, at times, once I got used to what intensive care was about I felt much more relaxed about and trusted them where as when she was in the
Concerns about care

anger

barriers to care

P: yeah but then saying that when she went home as well I sensed that dad wasn’t looking after her. I think he met her physical needs but he wasn’t very good at nurturing or comforting her.

I: yeah

Guilt from not completing obligation.

P: umm, so it was, it was frustrating and I felt guilty about not ensuring that things were right, still do.

I: yeah

Guilt long term

P: that is something that has stayed. And I also think that I just wanted to shake people, that they just didn’t understand, you know one of the doctors that we lodged a complaint with at LOCATION didn’t respond to the health care complaints recommendation that we go for mediation, he just didn’t respond, and then about 12 months later he did.

I: yeah
P: and I still am so angry about that and I just want to sit him down
and go, did you think about the impact this has

I: mmm

P: whereas if he had said no right from the beginning as one of the
other doctors, did, well that’s fine

I: that’s fine

P: that is absolutely fine, or if the nurse unit manager when we came
in and found that mum had fallen had simply said look this is
awful, I am sorry we are trying to find out what has happened, and
she didn’t, she was very much in sort of crisis control trying to
keep everything contained, and I can now on some level
understand why she didn’t apologise for it but that is all it would
have taken

I: that’s it, just that little human side of it

P: that’s it, yeah

I: yeah. Has your mum’s cancer changed the way you think about
your own health?
P: Yes, I went to the gym this morning. Well I don’t know if it’s the cancer, I guess I do find that whenever I get a twinge of something I want to go to the doctor and then I think no I’m being a hypochondriac, so I don’t go so in a way I may have become the opposite because I think that I am overreacting, umm but it is more all the complications that make me worry because I think if I get something like that I need to be in the best health to get over it, umm so I am over 40 and overweight and have the genes for type 2 diabetes so it is actually only been the last 6 months that I have actually felt that I can do something about that.

I: mmhmm

P: but yeah during that sort of three year period I have been having on and off different hypochondriac moments, yeah

I: yeah. Umm what are some of the activities to try and prevent yourself from getting cancer?

P: I don’t, I try to prevent myself from getting type 2 diabetes.

I: Fair enough
P: Well I don’t smoke but that is not about not having cancer it is just a disgusting habit in my book, umm so no all my health stuff all the exercise and eating right is all about not having type 2 diabetes and also the exercise I do is also wanting to be flexible so feeling if something does go wrong there is still a bit of a chance of recovering

I: yeah, and well type 2 diabetes is probably the more pressing risk as well

P: yes it is

I: Well that was actually my last question for today. Do you have anything about your experience that we haven’t discussed that you would like to

P: (pause) No I don’t think so
Appendix G: Summary of Scales Reviewed in Preparation of Study 2

Rationale:

Scales, which aim to assess the impact of cancer and/or psychosocial adjustment to cancer and illness, were initially reviewed to determine whether there was a pre-existing scale to measure the psychosocial dimensions of parental cancer, similar to those that emerged from Study One. The review resulted in very few measures that assess the experience from a family perspective. When a suitable scale was not found, a decision was made to create the Parental Cancer Questionnaire (PCQ), using the data from Study One for use in Study Two. The reviewed scales were then reconsidered as potential sources to assess the validity of the PCQ.

Most scales were deemed inappropriate due to their aim of assessing the impact of cancer/illness on the patient. Therefore their use as a source of validity on the Study Two target population was problematic, as there is no existing psychometric data in relation to the use of the scales on a third party. Also, the items were frequently irrelevant, as they assessed dimensions of the illness experience that would only be had by the patient (e.g., managing treatment side effects, body disfiguration). In the end, the decision was made to use multiple scales to assess the validity of the PCQ, scales that examined the separate components of the PCQ (i.e. benefit finding, emotional reactions, grief and loss, and issues relating to caregiving).

The following table summarises the key characteristics of the scales that were reviewed. Characteristics include information, where possible, about the theoretical orientation, test population, content and administration, reliability and validity, and a summary of their suitability (from this thesis author’s perspective) for use in Study Two.
SUMMARY OF SCALES RELATING TO IMPACT OF/ADJUSTMENT TO CANCER OR THE EXPERIENCE OF CHRONIC ILLNESS


**Name of Measure:** Brief Cancer Impact Assessment (BCIA)

**Theoretical Orientation**
Theoretical model not stated

**Test Population**
Sample consisted of 783 breast cancer survivors of mixed ethnic background.

**Content and Test Administration**
A brief 16 item measure that aims to assess both the positive and negative impact of cancer in long-term survivors. Using a 5-point scale, participants rate whether the impact in each area was negative, positive, or no impact.

Factor analysis suggests 4 factors are present:
(a) Caregiving and finances
(b) Exercise and diet behaviours
(c) Social and emotional functioning
(d) Religiosity

**Reliability**
Cronbach’s alphas for the subscales are reported as:
(a) Caregiving and finances $\alpha = 0.77$
(b) Exercise and diet behaviours $\alpha = 0.63$ (two items)
(c) Social and emotional functioning $\alpha = 0.75$
(d) Religiosity $\alpha = 0.81$

**Validity**
Suitable correlations between the BCIA and optimism, fear of recurrence, stress, posttraumatic growth and health-related QOL were observed, and are suggestive of the scale’s construct validity.

**Additional comments**
The developers argue that, despite the existence of valid measures of general functioning and symptoms of impact (i.e. depression) in cancer patients, there is a void in the area of valid measures that assess the perceived impact of cancer on life plans and activities.

**Suitability for use**
The strength of the scale is its ability to assess both positive and negative impact in the one measure. While the scale does include general areas of life (e.g. religiosity, social life, career plans/goals), rather than disease specific items (e.g. pain, side effects), there are few items that represent the themes identified in Study One. For example, there is no question that examines family relationships, and this was a central theme in Study One. Therefore it is felt that the scale is unsuitable for use in Study Two.


### Name of Measure: Sickness Impact Profile

<table>
<thead>
<tr>
<th>Theoretical Orientation</th>
<th>Test Population</th>
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<tbody>
<tr>
<td>No theoretical orientation, the measure aims to assess sickness-related dysfunction.</td>
<td>The SIP is a widely used tool that has demonstrated utility in a variety of populations with various diseases, including cancer.</td>
</tr>
</tbody>
</table>

### Content and Test Administration

The SIP consists of 136 items that require yes/no responses. Twelve dimensions:

- (a) Sleep and rest
- (b) Eating
- (c) Work
- (d) Home management
- (e) Recreation and pastimes
- (f) Ambulation
- (g) Mobility
- (h) Body care and movement
- (i) Social interactions
- (j) Alertness behaviour
- (k) Emotional Behaviour
- (l) Communication

### Reliability

Suitable internal consistency coefficients have been reported for the original SIP and various language translations. Overall SIP reliability ranges from 0.81 to 0.95, and dimension reliabilities are reported between 0.97 – 0.94.

Test-retest reliabilities range from 0.75-0.92 for overall SIP.

### Validity

The SIP has demonstrated suitable relationships with other health and functional status measures (e.g., ADL Index, Index of Well-Being). However, de Bruin et al. (2002) argue that reports of factor analysis to confirm the construct validity of the SIP are absent from the literature.

### Additional comments

Recognised as one of only three scales recommended for use in research examining quality of life and functional status.

### Suitability for use

Unsuitable, while the SIP is a very good measure, the content examines domains irrelevant to the target cohort. The length of the SIP would also be an issue in the planned study.

**Name of Measure:** Brief Illness Perception Questionnaire (Brief IPQ)

**Theoretical Orientation**
Leventhal’s self-regulatory model of perceived health threat.

**Test Population**
A total sample of 829 patients with various diagnoses was used in the scale development. However, not all participants were involved in all elements of scale design (i.e., test-retest reliability was assessed with a sample of 132 renal patients only).

**Content and Test Administration**
Eight items, rated on a 1-10 scale. Five of the items represent cognitive illness representations (e.g., consequences, personal control), two items represent emotional representations (e.g., concern) and one item assesses comprehensibility.

**Reliability**
Adequate test-retest reliability is reported. No overall internal consistency is reported.

**Validity**
The Brief IPQ demonstrated concurrent validity through correlations with the measure from which it was derived (the IPQ-R), and measures of self-efficacy. The Brief IPQ distinguishes between different illnesses, and was predictive in determining mental and physical recovery from myocardial infarction.

**Additional comments**
The test is a refinement of the longer (80 item) Illness Perception Questionnaire – Revised (IPQ-R). The items of the Brief IPQ were developed to summarise the content of the items contained within the subscales of the IPQ-R.

**Suitability for use**
Unsuitable, examines patient illness perceptions on dimensions not relevant to the target cohort (e.g., how much do you experience symptoms from your illness?).

**Name of Measure:** Not provided

<table>
<thead>
<tr>
<th>Theoretical Orientation</th>
<th>Test Population</th>
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</thead>
<tbody>
<tr>
<td>No theoretical orientation stated.</td>
<td>Small number of health professional (n= 3), prostate cancer patients and their partners (n = 14) developed items on the scale through focus groups and literature review.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Content and Test Administration</th>
<th>Reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ten items that are responded to on a five-point ordinal scale. Areas covered in the scale include: (a) Psychological issues relating to malignancy (b) Social and role functioning (c) Worries and concerns about symptoms and limitations.</td>
<td>Not reported.</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Validity</th>
<th>Additional comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authors suggest the scale has content validity, however, further testing is required to establish the psychometric properties of the measure.</td>
<td>Reflects the view that psychological issues are important to cancer patients and their partners, however, many surgeons may not have the skills to make such assessments.</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Suitability for use</th>
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<tbody>
<tr>
<td>Unsuitable, too specific to prostate cancer, requires further development to establish psychometric properties, some areas irrelevant to the target cohort (e.g., concerns regarding sexual functioning). However, it is an important acknowledgement that prostate cancer affects individuals other than the patient.</td>
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**Name of Measure:** Psychological Adjustment to Cancer (PAC)

<table>
<thead>
<tr>
<th>Theoretical Orientation</th>
<th>Test Population</th>
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<tbody>
<tr>
<td>Based on the premise that adjustment is a functional outcome of coping. Utilises the model proposed by Cohen and Lazarus (1979), outlining 5 main features of adaptation.</td>
<td>The final version of the scale was developed with a sample of 283 melanoma patients.</td>
</tr>
</tbody>
</table>
The scale was originally 53 items, but later reduced to the final 21 item measure. Items are scored using a 5-point Likert scale, indicating the level of agreement with the statement.

The two factors are:
(a) Impact of cancer
(b) Self-esteem and feelings of helplessness/hopelessness

Report highly significant correlations ($p < .0001$) between the PAC and criterion measures, such as the Functional Living Index for Cancer, the Hospital Anxiety and Depression Scale and the Profile of Mood States

Unsuitable: While many items on the impact of cancer subscale are highly relevant, and could be modified for use with the target cohort (e.g., If I did not have cancer I think I would be quite a different person), many items on the helplessness-hopelessness subscale are irrelevant (e.g., Since getting cancer my body has felt unclean).


**Name of Measure:** Illness Cognition Questionnaire

**Theoretical Orientation**
Cognitive theory that suggests that illness cognitions are mediators between stress and illness.

**Content and Test Administration**
An 18 item questionnaire, which utilises a 4-point Likert scale response format.

The scale contains 3 factors:
(a) Helplessness
(b) Acceptance
(c) Perceived benefits

**Reliability**
The internal consistencies of the subscales range from 0.71 to 0.80 for the impact subscale, and 0.82 to 0.85 for the self-esteem subscale.

**Validit**
Internal consistency alphas range from 0.84 to 0.91 for all subscales, with both samples.

**Test-retest correlations range from 0.68 to 0.79, over a one year period.**
**Validity**
Concurrent validity is demonstrated through relationships with health, personality dimensions, coping and social support variables. Predictive validity suggested through associations between acceptance and benefit finding and positive disease outcomes.

**Suitability for use**
Unsuitable, the benefit items are relevant, but a bit too broad, and there are no items looking at family or other interpersonal relationships. The items on the helplessness and acceptance subscales are largely irrelevant for non-patients and, therefore, could not be adopted for use with the target cohort.


**Name of Measure:** Reaction to the Diagnosis of Cancer Questionnaire

**Theoretical Orientation**
Positive psychology, acknowledging that patients also have confronting or optimistic reactions to diagnosis.

**Test Population**
441 ambulatory cancer patients with various diagnoses (i.e., breast, lymphatic, colorectal, lung and uterine/vaginal cancer).

**Content and Test Administration**
The 28 item scale contains two subscales:
(a) Distress
(b) Confrontation.

Participants respond using a 5-point Likert scale.

**Reliability**
Solid reliability has been reported, with a total RDCQ Cronbach alpha of .90, and the subscale reliability coefficients of $\alpha = .91$ for distress items and $\alpha = .82$ for confrontation items.

**Validit**
Not reported

**Suitability for use**
Suitable as a way of assessing validity of the experience intensity theme items on the PCQ. The content, especially the despair items, are very similar to the emotions reported by the participants in Study One (e.g. despair, anger, shock). Only examines the emotional elements of the reaction to diagnosis, not physical aspects, and therefore the questions are relevant. The scale could be easily modified for use with the target cohort by changing the question stem from “what do you remember feeling after you received your diagnosis of cancer” to “what do you remember feeling after you heard the diagnosis of your parent’s cancer?” The distress item wording can be largely unchanged, the confrontation items need to be modified, when the term cancer is used to “my parent’s cancer”

<table>
<thead>
<tr>
<th>Validity</th>
<th>Additional comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concurrent validity is demonstrated through relationships with health, personality dimensions, coping and social support variables. Predictive validity suggested through associations between acceptance and benefit finding and positive disease outcomes.</td>
<td>Assesses both positive and negative cognitions in a relatively brief scale.</td>
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**Name of Measure:** Questionnaire on Stress in Cancer Patients - Revised  

**Theoretical Orientation**  
No theoretical orientation stated.

**Content and Test Administration**  
A 23-item scale that examines potential everyday stressors for cancer patients. Respondents need to indicate whether the stress is relevant to them and, if yes, the degree to which the problem causes distress (on a 5-point scale).

Five sub-scales:  
(a) Psychosomatic complaints  
(b) Fears  
(c) Information deficits  
(d) Everyday life restrictions  
(e) Social strains

**Validity**  
Construct validity demonstrated through correlations with other measures of psychological functioning (e.g. HADS, SCL-90).

**Reliability**  
Only total score Cronbach’s alpha reported as 0.89.

**Additional comments**  
The original article detailing the scale’s development is in German only.

**Suitability for use**  
Unsuitable, although cancer-specific, most of the questions relate to physical elements of the disease (e.g., fear of returning to hospital, fear of pain) or psychological elements that would be specific to the patient (e.g., feeling less valued).


**Name of Measure:** Impact of Illness Scale (IIS)  

**Theoretical Orientation**  
Theoretical orientation not stated.

**Test Population**  
Three studies were undertaken for the scale development, one with a sample of 497 Turkish residents, the second with a sample of 684 community-based adults, and the third with 359 students from Australia and Japan.
Content and Test Administration

A brief 9 item scale that aims to measure the perceived restriction in psychosocial functioning, arising from illness. Participants indicate the extent to which each psychosocial aspect has been affected by illness over the past three months, using a 4-point Likert scale.

The scale covers the areas of relationships, work, leisure, religion, activities of daily living, family, mobility and cognition.

Validity

Construct validity demonstrated through correlation with measures of general functioning amongst illness groups.

Additional comments

Cross-cultural relationships are demonstrated, with little variation in response based on cultural identity. Not a cancer-specific scale.

Reliability

In the various samples, Cronbach’s alphas have ranged from 0.82 to 0.94.

Suitability for use

Unsuitable, the scale examines how illness disrupts regular routines and activities. While this did emerge as an issue, especially if the adult child was involved in caring, the scale does not consider positive changes arising from the experience. Also, as it is not a specific caregiving scale and, therefore, does not cover many care-related issues, it will not be used to assess the validity of the care items on the PCQ.


Name of Measure: Cancer Behaviour Inventory (Version 2.0)

Theoretical Orientation

Based on self-efficacy theory, which suggests that the higher a person’s confidence in their actions (i.e., coping) the higher the probability of goal attainment (i.e., quality of life).

Test Population

The scale was refined from the original 43 item scale, using a sample of 280 cancer patients.
### Content and Test Administration

The 33 item scale aims to measure self-efficacy for coping with cancer. Participants indicate their level of confidence in performing the coping behaviour, using a 9-point scale.

Factor analysis suggests that 7 dimensions are present:
1. Maintaining activity and independence
2. Seeking and understanding medical information
3. Stress management
4. Coping with treatment related side effects
5. Accepting cancer/Maintaining a positive attitude
6. Affective regulation
7. Seeking social support

### Reliability

Overall scale reliability is reported as $\alpha = 0.94$. The internal consistencies of the individual factors are:
1. Maintaining activity and independence $\alpha = 0.86$
2. Seeking and understanding medical information $\alpha = 0.88$
3. Stress management $\alpha = 0.86$
4. Coping with treatment side effects $\alpha = 0.82$
5. Accepting cancer/Maintaining a positive attitude $\alpha = 0.86$
6. Affective regulation $\alpha = 0.81$
7. Seeking social support $\alpha = 0.80$

Test-retest reliability reported as 0.74.

### Validity

Validity is reported in terms of relationships between stress management, quality of life measures and satisfaction with life.

### Additional comments

Authors suggest the scale has high utility in both research and clinical settings, as it enables monitoring of psychosocial treatments and the assessment of efficacy at various stages of the treatment of cancer.

### Suitability for use

Not suitable, many of the items do not relate to the aspects of experience that are reported by children of cancer patients. The main focus is on assessing self-efficacy in coping with the situation, rather than benefit finding, or examining the emotional intensity of the experience.

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**Name of Measure:** Psychosocial Adjustment to Illness Scale

**Theoretical Orientation**

Designed to examine psychosocial adjustment to illness (as opposed to having a scale examining outcome/impact of illness with a few psychosocial items).

**Test Population**

Originally developed on 37 patients with Hodgkin’s disease and 38 parents whose children had Hodgkin’s disease or solid tumours.
Content and Test Administration

Originally designed to be a semi-structured interview, the scale contains 45 items, which participants respond to using a 4-point scale. The scale was later refined to develop a self-report measure.

Seven subscales are present:
(a) Health care orientation
(b) Vocational environment
(c) Domestic environment
(d) Sexual relationships
(e) Extended family relationships
(f) Social environment
(g) Psychological distress

Validity

Morrow et al. (1978) report that the seven subscales are relatively independent of each other. Each subscale has also demonstrated significant correlations, in the anticipated direction, with other measures. For example, the psychological distress subscale is positively correlated with both patient and observer ratings of anxiety and depression.

Additional comments

Merluzzi and Martinez Sanchez (1997) suggest a slightly different factor structure emerges for cancer patients, namely, the merging of domestic and vocational items, and the creation of a help from others subscale.

A caregiver version is available (unable to find specific psychometric information on this version). The patient version has been modified for use with spouses and family members in previous research.

Suitability for use

The measure has been very widely used in research, particularly in the cancer-research field. Unsuitable, although the measure does contain some relevant items, along with many irrelevant sections (e.g. medical treatment, sexual relationships).


Name of Measure: Psychosocial Effects of Multiple Sclerosis Scale

Theoretical Orientation

Theoretical orientation not stated.

Test Population

50 MS patients provided qualitative descriptions of their experience, 94 MS patients completed the questionnaire derived from the interviews.
### Content and Test Administration
A 48 item scale that requires patients to indicate their level of agreement with each statement, using a 5-point scale.

Three factors are present:
(a) Demoralisation  
(b) Benefit finding  
(c) Deterioration in relationships

### Reliability
Overall scale reliability is $\alpha = 0.87$.

The factor reliabilities are:
(a) Demoralisation $\alpha = 0.90$  
(b) Benefit finding $\alpha = 0.84$  
(c) Deterioration in relationships $\alpha = 0.88$.

### Validity
Correlation evidence presented, demonstrating expected relationships between the psychosocial factors and measures of coping and affect.

### Additional comments
Scale was developed, based on qualitative responses of MS patients, in an attempt to gain insight into the psychosocial functioning of MS patients.

The scale has been modified by Katz, Flasher, Cacciapaglia and Fisher (2001) for use in cancer and lupus patients.

### Suitability for use
Not suitable, while many of the benefit items are relevant, and similar to the types of benefits reported in Study One, there is again the issue of many irrelevant items, due to the scale being designed to test a patient’s perspective, and therefore there is a focus on physical aspects of disease.

---


**Name of Measure:** Cancer Coping Questionnaire (CCQ)

**Theoretical Orientation**
Cognitive-behavioural outlook. Proposes that cognitive-behavioural therapy improves the psychological outcomes of people experiencing serious illness through its impact on coping.

**Test Population**
Sample consisted of 201 cancer patients with a variety of diagnoses (e.g., breast, melanoma, lung and prostate).

**Content and Test Administration**
A 21-item scale designed to measure both adaptive and maladaptive coping strategies. Participants respond, using a 4-point Likert scale, to indicate the frequency with which they have used a coping strategy.

**Reliability**
The Cronbach’s alpha for the individual coping items was 0.87, and interpersonal items was 0.82. The test-retest reliability was 0.90 (individual) and 0.84 (interpersonal).
Content and Test Administration continued

The scale is broken into two sections:

(a) Individual coping responses (4 subscales: coping, positive focus, diversion and planning)

(b) Interpersonal scale (completed only by participants who have partners. Contains items that reflect coping strategies that include the partner, such as discussing the impact of cancer).

Validity

The CCQ distinguished between patients with high and low psychological morbidity, and correlated as expected with measures of adjustment to cancer. The authors report that further assessment of the interpersonal scale is required to confirm its validity.

Additional comments

Test items were developed through the use of the Adjuvant Psychological Therapy handbook, and then refined from feedback with a patient cohort.

There are also two questions to gauge how stressful the patient has found their cancer in the preceding week.

Suitability for use

Unsuitable, the CCQ focuses on how patients cope with their disease. Although coping was mentioned by some participants in Study One, it has not emerged as a central theme.


Name of Measure: Benefit Finding in Multiple Sclerosis Caregiving Scale

Theoretical Orientation

Stress-related growth, identifying benefits from adversity.

Test Population

The sample consisted of 232 carers of people with multiple sclerosis.
Content and Test Administration

Originally a 55 item scale, which was developed through the use of qualitative data, and adjusting items on the benefit finding subscale of the Psychosocial Effects of Multiple Sclerosis Scale (Mohr et al., 1999, see above). Scale was reduced to 27-item scale through factor analysis. Participants respond using a 3-point Likert scale.

The six factors are:
(a) Enriched relationships
(b) Spiritual growth
(c) Family relations growth
(d) Lifestyle gains
(e) Inspiration
(f) Relationship opportunities

Validity

Demonstrated convergent validity through correlations with the Sense of Coherence scale for all factors except relationship opportunities. External validity demonstrated through correlations with the care recipient’s ratings of caregiver benefit finding.

Suitability for use

The strength of the scale is that it examines benefits from a caregiver, rather than a patient, perspective. Therefore, many of the items are highly relevant, and reflect similar sentiments to the data found in Study One. However, it is unsuitable for use, as several items relate specifically to the caregiving role (e.g., giving back to the patient, valuing the opportunity to care and provide support), and many adult children do not provide care to their parents.

Reliability

The overall scale reliability is 0.92. The reported internal consistency alphas for the factors are:
(a) Enriched relationships = 0.87
(b) Spiritual growth = 0.87
(c) Family relations growth = 0.86
(d) Lifestyle gains = 0.80
(e) Inspiration = 0.78
(f) Relationship opportunities = 0.78

Additional comments


Name of Measure: The Parental Illness Impact Scale (Parkinson’s Disease)

Theoretical Orientation

Theoretical orientation not stated, but based on the argument that illness affects entire family units, not just patients.

Test Population

Eight-nine children of Parkinson’s disease patients, 17 completed the 12-18 version, and 72 completed the 19+ version.
Content and Test Administration

Developed through 29 semi-structured interviews with both adolescents and adult children with a parent diagnosed with Parkinson’s disease.

A 38-item scale containing 6 factors:
(a) Social development/independence and responsibility
(b) Burden of daily help
(c) Communication and understanding
(d) Impact on personal future
(e) Impact on family functioning
(f) Friends reactions

The response options vary from a 5-point Likert scale to yes/no, depending on the question.

Validity

Concurrent validity established through correlations with measures of quality of life, self-esteem and depression, as well as an examination of differences in sub-scale scores across demographic variables, such as current age, age at diagnosis, and duration of illness.

Reliability

The factor alpha values are reported as:
(a) Social development/independence and responsibility = 0.91
(b) Burden of daily help = 0.88
(c) Communication and understanding = 0.89
(d) Impact on personal future = 0.79
(e) Impact on family functioning = 0.68
(f) Friends reactions = 0.62

Additional comments

The authors argue that research into the impact of illness on the patient’s children (young or adult) is hampered by the lack of suitable tools.

Suitability for use

Unsuitable. Personal correspondence with the authors suggests that modification of the scale to be more relevant to parental cancer would be possible. However, the scale that they provided me did not completely correspond with the reported measure (reported measure = 38 items, provided measure = 57 items). While there is clearly some match between some items in Table 2 of the reported measure, others are missing, and some are ambiguous. Therefore, it is impossible to determine the psychometric properties of what I was provided for use. Also, the authors provided me with the 19+ version, which contains some irrelevant items (e.g. bullying – which may reflect the differences in physical symptoms of Parkinson’s disease and cancer).

**Name of Measure:** The Distress Inventory – Cancer

<table>
<thead>
<tr>
<th><strong>Theoretical Orientation</strong></th>
<th><strong>Test Population</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Theoretical orientation not stated.</td>
<td>63 head and neck cancer patients awaiting treatment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Content and Test Administration</strong></th>
<th><strong>Reliability</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>A 26 item self-report measure, which utilises a five-point Likert scale response format. The scale aims to assess distress arising from illness, which may not be severe enough to reach diagnostic levels of psychological disturbance.</td>
<td>Reliability is reported as $\alpha = 0.85$.</td>
</tr>
</tbody>
</table>

Factor analysis revealed four domains:
(a) Psychological
(b) Spiritual
(c) Physical
(d) Family

<table>
<thead>
<tr>
<th><strong>Validity</strong></th>
<th><strong>Additional comments</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Authors report face and factorial validity.</td>
<td>Developed to address the void in illness-specific distress scales (i.e., although many distress measures exist, there are very few that look at illness-related distress, and only one other that focuses on cancer).</td>
</tr>
</tbody>
</table>

**Suitability for use**

Unsuitable, many items relate to treatment and physical symptoms and, therefore, cannot be modified for use with the target cohort. Although distress was an element of the experience intensity and grief and loss themes, the elements of distress assessed in this scale are different to the sentiments expressed by participants in Study One.
Name of Measure: Mental Adjustment To Cancer Scale (MAC)

Theoretical Orientation
Theoretical orientation not stated.

Test Population
The MAC was developed, utilising a sample of 235 cancer patients with a variety of diagnoses.

The replication study by Osbourne et al. contained a sample of 632 breast cancer patients.

Content and Test Administration
The MAC is designed to measure a patient’s adjustment style. The scale consists of 40 items, and uses a 4-point response format.

The original MAC contained the following factors:
(a) Helplessness/hopelessness
(b) Anxious preoccupation
(c) Fatalism
(d) Fighting spirit

Reliability
The factor structure of the MAC has been consistently unstable, with less than optimal reliability alphas consistently reported for the anxious preoccupation and fatalism subscales. Revised structures (i.e., Osborne et al. suggest 6 factors) also demonstrate unreliable subscales.

Validity
Concurrent validity is demonstrated through a relationship with related measures, such as the Medical Coping Models Questionnaire and the Hospital Anxiety and Depression Scale.

Additional comments

Suitability for use
Personal correspondence with Dr Maggie Watson in June 2007 suggested that the MAC would not be suitable for modification for use with the target cohort.
<table>
<thead>
<tr>
<th><strong>Name of Measure:</strong> Mini-Mental Adjustment to Cancer Scale (Mini-MAC)</th>
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</thead>
<tbody>
<tr>
<td><strong>Theoretical Orientation</strong></td>
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<tr>
<td>Theoretical orientation not stated.</td>
</tr>
<tr>
<td><strong>Content and Test Administration</strong></td>
</tr>
<tr>
<td>The Mini-MAC is a 29 item questionnaire that employs a 4-point response scale.</td>
</tr>
<tr>
<td>The Mini-MAC widens the scope of the MAC, by including items on avoidance. The five factors of the Mini-MAC are:</td>
</tr>
<tr>
<td>(a) Helpless-hopeless</td>
</tr>
<tr>
<td>(b) Anxious preoccupation</td>
</tr>
<tr>
<td>(c) Fighting Spirit</td>
</tr>
<tr>
<td>(d) Cognitive avoidance</td>
</tr>
<tr>
<td>(e) Fatalism</td>
</tr>
<tr>
<td><strong>Validity</strong></td>
</tr>
<tr>
<td>Report validity correlations between the Mini-MAC, the original MAC and the Hospital Anxiety and Depression scale.</td>
</tr>
<tr>
<td><strong>Suitability for use</strong></td>
</tr>
<tr>
<td>Personal correspondence with Dr Maggie Watson in June 2007 suggested that the Mini-Mac would not be suitable for modification for use with the target cohort.</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th><strong>Name of Measure:</strong> Impact of Cancer Instrument (IOC)</th>
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<tbody>
<tr>
<td><strong>Theoretical Orientation</strong></td>
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<tr>
<td>Theoretical orientation not stated.</td>
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</tbody>
</table>
An 81 item measure, which is designed to measure aspects of long-term cancer survivorship. The self-report scale utilises a 5-point response format.

Ten subscales:
(a) Health awareness
(b) Body changes
(c) Positive self-evaluation
(d) Negative self-evaluation
(e) Positive outlook
(f) Negative outlook
(g) Life interferences
(h) Value of relationships
(i) Meaning of cancer
(j) Health worry

Reliability coefficients for the subscales are reported to range from a low of $\alpha = 0.67$ for life interferences to a high of 0.99 for value of relationships. Nine of the 10 subscales report alphas exceeding 0.70.

Concurrent validity demonstrated through correlations with the SF-36, quality of life - cancer survivors and the posttraumatic growth inventory. Discriminant validity data is also presented.

Some subscales only have 2-3 items, making reliability and the factor structure potentially unstable. Developers suggest that confirmatory factor analysis of the scale is warranted.

Some reliability concerns (i.e., too low or very high in short subscales), however, a strength of the scale is that it does look at both positive and negative elements of the experience. Unsuitable for use, due to a number of irrelevant items and no consideration of care issues.
Appendix H: Study Two On-line Survey

Section 1: Demographics

Please provide us with the following information about yourself to help us describe our participants.

Your Age:
- □ 18 – 25
- □ 26 – 30
- □ 31 – 35
- □ 36 – 40
- □ 41 – 45
- □ 46 – 50
- □ 51 – 55
- □ 56 – 60
- □ 61 – 65
- □ 66 – 70
- □ Over 70

Your Gender:
- □ Male
- □ Female

Have you ever been diagnosed with cancer?
- □ Yes
- □ No

What is your postcode?  


How many brothers or sisters do you have?  Brothers □  Sisters □

What is your occupation? (Please list home duties, care activities or voluntary work in the box titled “other” if such activities are your main work role. If you are unsure of the category, please write your occupation in the box titled “other”).

☐ Manager/Administrator (e.g. General Manager, Finance Manager, Farmer)

☐ Professional (e.g. Engineer, Accountant, Computing Professional, Registered Nurse, Veterinarian, Teacher, Social Worker, Actor)

☐ Associate Professional (e.g. Medical Technical Officers, Chef, Supervisor, Enrolled Nurse, Mortgage Broker, Police Officer)

☐ Tradespersons (e.g. Fitter and Turner, Mechanic, Carpenter, Bricklayer, Painter, Baker, Greenkeeper, Printer, Hairdresser)

☐ Advanced Clerical & Service Worker (e.g. Secretary, Bookkeeper, Insurance Agent, Keyboard Operator)

☐ Intermediate Clerical, Sales & Service Worker (e.g. Receptionist, Accounts Clerk, Bank Teller, Sales Rep, Child Care Worker, Waiter)

☐ Intermediate Production & Transport Worker (e.g. Forklift Driver, Crane Operator, Bus Driver, Miner, Store person)

☐ Elementary Clerk, Sales & Service Worker (e.g. Filing Clerk, Office Trainee, Mail Clerk, Service Station Attendant, Security Guard)

☐ Labourers (e.g. Cleaner, Process Worker, Packer, Farm Hand, Kitchen Hand, Concreter)

☐ Other (please specify)
Which religion/religious denomination do you identify with?

- □ Anglican
- □ Buddhist
- □ Catholic
- □ Church of England
- □ Jewish
- □ Lutheran
- □ Muslim
- □ Presbyterian
- □ Uniting
- □ No religious affiliation
- □ Other (please specify)

Demographics: Your Parent’s Cancer

The following questions relate to your parent’s cancer. Although participation in the study is anonymous and the researcher will make no attempt to contact your parent please be aware that answering the following questions may be viewed by some people as a breach of patient privacy. As such it is suggested that you consider your parent’s attitude and level of comfort with discussing their cancer and answer only the questions you believe your parent would willingly answer themselves.

Which parent was diagnosed with cancer? NOTE: This survey is designed to collect information on one parent. If both of your parents were diagnosed with cancer please select one to be the focus of the survey.

- □ Mother
- □ Father
- □ Step-Mother
- □ Step-Father
How old were **YOU** when your parent was diagnosed with cancer?

How old was **YOUR PARENT** when they were diagnosed with cancer?

- □ 34 or younger
- □ 35 - 39
- □ 40 – 44
- □ 45 – 49
- □ 50 – 54
- □ 55 – 59
- □ 60 – 64
- □ 65 – 69
- □ 70 – 74
- □ 75 – 79
- □ 80 – 84
- □ 85 – 89
- □ 90 and over

In what year (approximately) was your parent diagnosed with cancer (e.g. 1998, 2005)?
What type of cancer did your parent have? (Please only provide information about the site of your parent’s primary cancer. Stage information and secondary sites are not required).

- [ ] Bladder Cancer
- [ ] Bowel Cancer
- [ ] Breast Cancer

- [ ] Cancer of Unknown Primary Site
- [ ] Central Nervous System Cancer (including brain & spinal cord cancers)
- [ ] Cervical Cancer

- [ ] Head and Neck Cancer (including mouth, tongue & larynx cancer)
- [ ] Kidney Cancer
- [ ] Leukaemia

- [ ] Liver Cancer
- [ ] Lung Cancer
- [ ] Lymphoma (inc Hodgkin's Disease & Non-Hodgkin’s lymphoma)

- [ ] Oesophageal Cancer
- [ ] Ovarian Cancer
- [ ] Pancreatic Cancer

- [ ] Prostate Cancer
- [ ] Skin Cancer (including melanoma, basal cell carcinoma & squamous cell carcinoma)
- [ ] Stomach Cancer

- [ ] Testicular Cancer
- [ ] Uterine Cancer
- [ ] Other (please specify)
What was the outcome of your parent’s cancer?

- □ Successful treatment (i.e. parent is currently cancer free)
- □ Still undergoing treatment
- □ Treatment but with recurrence or spreading of cancer
- □ Deceased
- □ Other (please specify)

What was/is the duration of your parent’s cancer experience (i.e. from diagnosis to the current day OR end of treatment OR recovery OR passing away)?

- □ Less than 6 months
- □ 6-12 months
- □ 1 – 2 years
- □ 2 – 3 years
- □ 3- 4 years
- □ 4- 5 years
- □ 5 years +
How long has it been since your parent recovered or passed away? NOTE: If you parent is still undergoing treatment please write YES in the box titled “Treatment Ongoing”.

Years [ ] Months [ ] Treatment ongoing [ ]

Prior to the diagnosis of cancer your parent’s health was:

☐ Excellent, no major health complaints

☐ Very good, 1-2 minor complaints that were well managed

☐ Good, some health issues and/or chronic conditions with adequate treatment

☐ Fair, some health issues and/or chronic conditions that caused concern, adequate treatment may or may not have been received

☐ Poor, multiple health issues and/or chronic conditions with inadequate or no treatment being received.
**Section 2: Parental Cancer Questionnaire**

The following statements relate to your experience of having a parent with cancer and the way your parent’s cancer has affected various aspects of your life. Please read each statement and circle the response that best indicates your level of agreement with each statement. Please provide only one response for each statement.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Very strongly disagree</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
<th>Very strongly agree</th>
<th>Does not apply to me</th>
</tr>
</thead>
<tbody>
<tr>
<td>I became closer to my sick parent during his/her cancer...................</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I have gotten to know my sick parent on a more meaningful level...........</td>
<td>1</td>
<td>2</td>
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<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>Communication between my sick parent and me improved.......................</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
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<tr>
<td>My sick parent and I enjoyed a broader range of activities together after he/she was diagnosed................................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I developed a greater respect for my sick parent as a result of his/her cancer experience......................................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
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<tr>
<td>My parent’s cancer gave me a chance to resolve past problem/s with my sick parent.............................................................</td>
<td>1</td>
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<td>5</td>
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</tr>
<tr>
<td>My relationship with my healthy parent improved as a result of my parent’s cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>My relationship with at least one of my siblings improved as a result of my parent’s cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>My relationship with other family members (e.g. spouse, own children, uncle, grandparents) improved as a result of my parent’s cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I have a greater sense of connection with my family since my parent was diagnosed with cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>My parent’s cancer has helped me recognise the importance and value of family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>Since my parent was diagnosed with cancer I make an effort to spend more time with family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>My parent’s cancer helped me recognise the importance of my personal relationships</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>As a result of my parent’s cancer I re-evaluated my career path</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
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<tr>
<td></td>
<td>Very strongly disagree</td>
<td>Strongly disagree</td>
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<td>Agree</td>
<td>Strongly agree</td>
<td>Very strongly agree</td>
<td>Does not apply to me</td>
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</tr>
<tr>
<td>My parent’s cancer changed my outlook on life for the better...</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I have been more willing to try new things since my parent was diagnosed with cancer...</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I have achieved a better balance between work/study and home since my parent has had cancer...</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>As a result of my parent’s cancer I try to make the most out of life...</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>Since my parent was diagnosed with cancer I make an effort to spend more time with people I care about, other than my family (e.g. friends, neighbours)...</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I feel that my experience with my parent’s cancer has made me more emotionally mature...</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I have developed an enhanced sense of spirituality/religiosity as a result of my parent’s cancer...</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I feel I have become more resilient as a result of what I went through when my parent was sick...</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
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<td>-------</td>
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<td>---------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>As a result of my parent’s cancer I now engage in activities that help me reduce my own risk of getting cancer (e.g. dietary changes, sun protection, discussed my cancer risk with my doctor)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I value my own health more since my experience of parental cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>Since my parent had cancer I have developed a greater sense of empathy for others</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>My parent’s cancer has been a traumatic experience for me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I feel/felt emotionally numb during my parent’s cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I feel/felt very isolated from other people during my experience of parental cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I am/was angry that my parent developed cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I feel/felt helpless when my parent is/was sick</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I would describe my parent’s cancer as the most emotionally difficult thing I have had to go through</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>Statement</td>
<td>Very strongly disagree</td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
<td>Very strongly agree</td>
<td>Does not apply to me</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------------------</td>
<td>-------------------</td>
<td>----------</td>
<td>----------------------------</td>
<td>-------</td>
<td>----------------</td>
<td>---------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>I was devastated by my parent’s cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I was shocked when my parent was diagnosed with cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I have been unable to accept why my parent got cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>My parent’s cancer made me doubt my beliefs (e.g. religion, faith, views on health and medicine, karma)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I feel haunted by memories of my parent’s suffering</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I feel that I have missed out on important times with my parent (e.g. having him/her present at weddings, opportunities to seek advice) as a result of his/her cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I feel that cancer changed the type of person my sick parent was so that I no longer really knew him/her</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I feel great sadness when I think about my parent’s cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>My parent’s cancer increased my responsibilities and duties</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>My role within my family changed as a result of my parent’s cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>All/most of my family members helped look after my parent when he/she was sick</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>My parent asked me for advice before making decisions about his/her care or treatment</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I had to change my plans (e.g. vacations, work activities, study) as a result of my parent’s cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I had to make big changes to my regular activities as a result of my parent’s cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>At times I resented the disruption that my parent’s cancer brought to my life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>Caring for my parent gave me a sense of control</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I feel/felt troubled by a great sense of responsibility for my parent during his/her illness</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I was stressed by my involvement in my parent’s care</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
<tr>
<td>I felt angry that my life was changed because of my parent’s cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>NA</td>
</tr>
</tbody>
</table>
I feel/felt there was nobody to assist or support me in caring for my parent.......................... 1 2 3 4 5 6 7 NA

My parent's cancer made it difficult for me to do the things I wanted to do............................................................... 1 2 3 4 5 6 7 NA

I found it hard to juggle my obligations during my parent's illness (e.g. work, caregiving, family, leisure activities)......................... 1 2 3 4 5 6 7 NA
Section 3: Posttraumatic Growth Inventory

Indicate for each of the statements below the degree to which this change occurred in your life as a result of your parent having cancer, using the following scale:

0= I did not experience this change as a result of my parent’s cancer.
1= I experienced this change to a very small degree as a result of my parent’s cancer.
2= I experienced this change to a small degree as a result of my parent’s cancer.
3= I experienced this change to a moderate degree as a result of my parent’s cancer.
4= I experienced this change to a great degree as a result of my parent’s cancer.
5= I experienced this change to a very great degree as a result of my parent’s cancer.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>I changed my priorities about what is important in life</td>
<td>0</td>
</tr>
<tr>
<td>I have a greater appreciation for the value of my own life</td>
<td>0</td>
</tr>
<tr>
<td>I developed new interests</td>
<td>0</td>
</tr>
<tr>
<td>I have a greater feeling of self-reliance</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>No change</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>I have a better understanding of spiritual matters</td>
<td>0</td>
</tr>
<tr>
<td>I more clearly see that I can count on people in times of trouble</td>
<td>0</td>
</tr>
<tr>
<td>I established a new path for my life</td>
<td>0</td>
</tr>
<tr>
<td>I have a greater sense of closeness with others</td>
<td>0</td>
</tr>
<tr>
<td>I am more willing to express my emotions</td>
<td>0</td>
</tr>
<tr>
<td>I know better that I can handle difficulties</td>
<td>0</td>
</tr>
<tr>
<td>I am able to do better things with my life</td>
<td>0</td>
</tr>
<tr>
<td>I am better able to accept the way things work out</td>
<td>0</td>
</tr>
<tr>
<td>I can better appreciate each day</td>
<td>0</td>
</tr>
<tr>
<td>New opportunities are available which wouldn't have been otherwise</td>
<td>0</td>
</tr>
<tr>
<td>I have more compassion for others</td>
<td>0</td>
</tr>
<tr>
<td>Statement</td>
<td>No change</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>I put more effort into my relationships</td>
<td>0</td>
</tr>
<tr>
<td>I am more likely to try to change things which need changing</td>
<td>0</td>
</tr>
<tr>
<td>I have a stronger religious faith</td>
<td>0</td>
</tr>
<tr>
<td>I discovered that I am stronger than I thought I was</td>
<td>0</td>
</tr>
<tr>
<td>I learned a great deal about how wonderful people are</td>
<td>0</td>
</tr>
<tr>
<td>I better accept needing others</td>
<td>0</td>
</tr>
</tbody>
</table>
Section 4: Caregiving Involvement

Were you able to be involved in caring for your parent during their cancer?

☐ Yes  ☐ No (please go to next page)

If yes, on a scale of 1-10, what level of involvement would you say represents your participation in your parent’s care (Circle the number that best matches your involvement)

<table>
<thead>
<tr>
<th>My involvement in my parent's care:</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Slight involvement</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I provided full-time care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please continue survey on page ##.
If no, what prevented you from being involved in caring for your parent (tick all that apply)?

☐ I chose not to engage in care activities

☐ Geographical distance

☐ Workload

☐ My own family (i.e. obligations to partner and/or children)

☐ Other family members were caring for my parent

☐ My parent asked me not to

☐ I felt I didn’t have the skills required

☐ Fear of cancer

☐ I was already caring for someone else

☐ Other (please specify)

Please continue survey on page ##.
### Section 4: Caregiving Difficulties and Satisfactions

NOTE: Only complete this section if you were involved in your parent’s care. If you were not involved in your parent’s care please continue the survey at Section 5, on page ##. If you are no longer caring for your parent but were involved in care at some stage please complete the questionnaires, reflecting back on the time when you were caring for your parent.

This questionnaire is a series of statements which carers have made about the difficulties they face. Carefully read each statement and show if it applies by circling the number that matches your level of stress.

<table>
<thead>
<tr>
<th>Caring can be difficult because:</th>
<th>This does not apply to me</th>
<th>Not Stressful</th>
<th>Stressful</th>
<th>Very Stressful</th>
</tr>
</thead>
<tbody>
<tr>
<td>I don’t have enough private time for myself...........................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I can feel helpless/not in control of the situation...............</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I can’t devote enough time to other family members...............</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>It causes financial difficulties......................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>The person I care for can play me up................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>The person I care for is immobile/has problems getting about....</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Professional workers don’t seem to appreciate the problems carers face..</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>It restricts my social life/outside interests........................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Caring can be difficult because:</td>
<td>This does not apply to me</td>
<td>Not Stressful</td>
<td>Stressful</td>
<td>Very Stressful</td>
</tr>
<tr>
<td>------------------------------------------------------------------------------------------------</td>
<td>---------------------------</td>
<td>---------------</td>
<td>-----------</td>
<td>----------------</td>
</tr>
<tr>
<td>It can put a strain on family relationships.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>It is physically tiring.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>The person I care for can demand too much of me.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I no longer have a meaningful relationship with the person I care for.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>The person I care for needs a lot of help with personal care.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>The person I care for doesn't always help as much as they could.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>My sleep is affected.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Relatives don't keep in touch as often as I'd like.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I feel angry about the situation.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I can't see friends as often as I'd like.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>My emotional well-being suffers.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I can't have a break or take a holiday.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>My standard of living has fallen.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>The person I care for doesn't always appreciate what I do.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Caring can be difficult because:

<table>
<thead>
<tr>
<th></th>
<th>This does not apply to me</th>
<th>Not Stressful</th>
<th>Stressful</th>
<th>Very Stressful</th>
</tr>
</thead>
<tbody>
<tr>
<td>My physical health has suffered.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>The person I care for is incontinent.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>The behaviour of the person I care for is a problem.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>There is no satisfaction to be gained from caring.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I don’t get enough help from health and social services.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Some family members don’t help as much as they could.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I can’t relax because I worry about caring.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I feel guilty about the situation.</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
This questionnaire contains a series of statements which carers have made about the satisfactions they have experienced. Carefully read each statement and show if it applies by circling the number that matches your level of satisfaction.

<table>
<thead>
<tr>
<th>Caring can be satisfying because:</th>
<th>This does not apply to me</th>
<th>No real satisfaction</th>
<th>Quite a lot of satisfaction</th>
<th>A great deal of satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring has allowed me to develop new skills and abilities..............................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>The person I care for is appreciative of what I do..................................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Caring has brought me closer to the person I care for...........................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>It's good to see small improvements in their condition...................................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I am able to help the person I care for reach their full potential...............................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I am able to repay their past acts of kindness..........................................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Caring provides a challenge...................................................................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Despite all their problems the person I care for does not grumble or moan..............</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>It is nice to see the person I care for clean, comfortable and well turned out........</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Caring enables me to fulfil my sense of duty..........................................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I am the sort of person who enjoys helping people........................................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Caring can be satisfying because:</td>
<td>This does not apply to me</td>
<td>No real satisfaction</td>
<td>Quite a lot of satisfaction</td>
<td>A great deal of satisfaction</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>---------------------------</td>
<td>----------------------</td>
<td>-----------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>I get pleasure from seeing the person I care for happy..........................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>It's good to help the person I care for overcome difficulties and problems....</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>It's nice when something I do gives the person I care for pleasure...............</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Knowing the person I care for the way I do means I can give better care than anyone else..........................................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Caring has helped me grow and develop as a person..................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>It's nice to feel appreciated by those family and friends I value................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Caring has strengthened close family ties and relationships........................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>It helps to stop me from feeling guilty................................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I am able to keep the person I care for out of an institution........................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I feel that if the situation were reversed, the person I care for would do the same for me......................................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I am able to ensure that the person I care for has their needs tended to........</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Caring has given me the chance to widen my interests and contacts...............</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Caring can be satisfying because:</td>
<td>This does not apply to me</td>
<td>No real satisfaction</td>
<td>Quite a lot of satisfaction</td>
<td>A great deal of satisfaction</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------------------------</td>
<td>---------------------------</td>
<td>----------------------</td>
<td>-----------------------------</td>
<td>----------------------------</td>
</tr>
<tr>
<td>Maintaining the dignity of the person I care for is important to me.........................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I am able to test myself and overcome difficulties..................................................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Caring is one way of showing my faith....................................................................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Caring has provided a purpose in my life that I did not have before.......................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>At the end of the day I know I will have done the best I could............................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Caring is one way of expressing my love for the person I care for..........................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Caring makes me feel needed and wanted...............................................................................</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Section 5: Emotional Responses

What do you remember of your feelings after you heard the diagnosis of your parent’s cancer?

<table>
<thead>
<tr>
<th>Feeling</th>
<th>No, I did not feel that way</th>
<th>Yes I felt that way a little</th>
<th>Yes, I felt that way moderately</th>
<th>Yes, I felt that way quite a bit</th>
<th>Yes, I felt that way extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was scared</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I was upset</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I was stunned</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I was depressed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I was worried about the future</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I felt despair</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I cried</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Why my parent?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I felt helpless</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I was numbed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I was angry</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I was uncertain about the future</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I could not understand why my parent had cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>What do you remember of your feelings after you heard the diagnosis of your parent’s cancer?</td>
<td>No, I did not feel that way</td>
<td>Yes I felt that way a little</td>
<td>Yes, I felt that way moderately</td>
<td>Yes, I felt that way quite a bit</td>
<td>Yes, I felt that way extremely</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>I knew my parent was doomed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I knew my parent was going to die</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I refused to believe it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I refused to accept the diagnosis</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I felt there was nothing to worry about</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I felt the diagnosis was a mistake</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I decided my parent’s cancer would not get the best of me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I decided to help my parent conquer the cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I decided to help my parent beat the cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I was optimistic about how things would turn out</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I decided to make the best of it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I decided my parent’s cancer would not change my life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I began to hope</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I accepted it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I refused to feel sorry for myself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
The following statements represent feelings and attitudes that some people express when they experience a loss. Loss may be associated with the death of your parent and/or the negative changes that occurred while your parent was sick. You may also be in a position where you are expecting a loss to occur.

Please reflect on the time when your parent was sick and consider how this experience has impacted upon you. Answer the statements as you are feeling now. Read each statement carefully and circle the number which most closely reflects your level of distress.

<table>
<thead>
<tr>
<th>Reflecting on my parent’s cancer...</th>
<th>No distress, never</th>
<th>Slightly distressful, a little bit of the time</th>
<th>Quite distressful, quite a bit of the time</th>
<th>Exceedingly distressful, continuously, a lot of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall, how much have thoughts and feelings about your loss/es distressed you ............</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have you experienced images of the events surrounding your parent’s cancer...............</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have thoughts of your loss or your loss situation come into your mind whether you wish it or not....................................................................................................................................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have you been reminded by people or familiar objects (photos, possessions, rooms, etc) of the loss or loss situation............................................................................................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have you found yourself yearning for the loss, or that the loss will not occur....................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have you found yourself imagining that the loss has/will not occur............................................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have thoughts or reminders of the loss or the loss situation caused you to feel dread......</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Reflecting on my parent's cancer...

<table>
<thead>
<tr>
<th></th>
<th>No distress, never</th>
<th>Slightly distressful, a little bit of the time</th>
<th>Quite distressful, quite a bit of the time</th>
<th>Exceedingly distressful, continuously, a lot of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you felt distress if for any reason you are confronted with the reality that the loss has occurred/will occur.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have reminders of the loss, or the loss situation, such as people, photos, situations, music, places etc caused you to feel longing for the loss or that the loss will not occur.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have reminders of the loss, or the loss situation such as people, photos, situations, music, places etc caused you to feel sadness.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have thoughts or reminders of the loss or the loss situation caused you to feel numb.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have thoughts or reminders of the loss caused you to feel guilt.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have thought or reminders of the loss or loss situation caused you to feel anger.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have thoughts about your loss made you more irritable with others.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have thoughts of your loss made it difficult for you to concentrate, remember things, or make decisions.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Have thoughts or reminders of what is or will be lost caused you to feel sick or ill in any way (e.g. generally unwell, loss of energy, headaches, dizziness, etc), other than from existing illness or disability.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
### Section 6: Psychological Outcomes

Please read each statement and circle a number 0, 1, 2, or 3 which indicates how much the statement applied to you over the past two weeks. There are no right or wrong answers. Do not spend too much time on any statement.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Did not apply to me at all</th>
<th>Applied to me to some degree, or some of the time</th>
<th>Applied to me a considerable degree, or a good part of the time</th>
<th>Applied to me very much, or most of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found it hard to wind down.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I was aware of dryness of my mouth.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I couldn’t seem to experience any positive feeling at all.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion).</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I found it difficult to work up the initiative to do things.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I tended to over-react to situations.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I experienced trembling (e.g. in the hands).</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt that I was using a lot of nervous energy.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Did not apply to me at all</td>
<td>Applied to me to some degree, or some of the time</td>
<td>Applied to me a considerable degree, or a good part of the time</td>
<td>Applied to me very much, or most of the time</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------------------------</td>
<td>----------------------------</td>
<td>--------------------------------------------------</td>
<td>---------------------------------------------------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>I was worried about situations in which I might panic and make a fool of myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt that I had nothing to look forward to</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I found myself getting agitated</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I found it difficult to relax</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt downhearted and blue</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I was intolerant of anything that kept me from getting on with what I was doing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt I was close to panic</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I was unable to become enthusiastic about anything</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt I wasn’t worth much as a person</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt that I was rather touchy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Did not apply to me at all</td>
<td>Applied to me to some degree, or some of the time</td>
<td>Applied to me a considerable degree, or a good part of the time</td>
<td>Applied to me very much, or most of the time</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------------------</td>
<td>-----------------------------</td>
<td>-------------------------------------------------</td>
<td>-------------------------------------------------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt scared without any good reason</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt that life was meaningless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Below are some statements about feelings and thoughts. Please circle the number that best describes your experience of each over the last two weeks.

<table>
<thead>
<tr>
<th>Statement</th>
<th>None of the time</th>
<th>Rarely</th>
<th>Some of the time</th>
<th>Often</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>I've been feeling optimistic about the future</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I've been feeling useful</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I've been feeling relaxed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I've been feeling interested in other people</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I've had energy to spare</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I've been dealing with problems well</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I've been thinking clearly</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I've been feeling good about myself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I've been feeling close to other people</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I've been feeling confident</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I've been able to make up my own mind about things</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I've been feeling loved</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I've been interested in new things</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I've been feeling cheerful</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Are there any comments or information you would like to add regarding your experience of having a parent with cancer, or your participation in this study? If so, please provide details in the box below.

How did you find out about the current study?

☐ Charles Sturt University electronic communications
☐ Link on a cancer organisation website
☐ Received Information Sheet from support group
☐ Direct contact by researcher
☐ Other (please specify): ______________________
Appendix I: Study Two Ethics Approval

11 November 2009

Mrs Janelle Levesque
7 Orlando Crescent
Voyager Point
NSW 2172

Dear Mrs Levesque,

Thank you for the additional information forwarded in response to a request from the Human Research Ethics Committee.

The Committee has now approved your proposal entitled “Investigating parental cancer: Psychological benefits, emotional reactions and involvement in caregiving” for a twelve month period from 11/11/2009. The protocol number issued with respect to this project is 2009/163. Please be sure to quote this number when responding to any request made by the Committee.

You must notify the Committee immediately should your research differ in any way from that proposed.

You are also required to complete a Progress Report form, which can be downloaded from www.csu.edu.au/research/forms/ehre_aanrep.doc, and return it on completion of your research project or by 11/11/2010 if your research has not been completed by that date.

Please don’t hesitate to contact the Executive Officer on telephone (02) 6338 4628 or email ethics@csu.edu.au if you have any enquiries.

Yours sincerely,

Julie Hicks
Executive Officer
Human Research Ethics Committee
C/o Associate Professor Darryl Mckay Dr Philip Elkinborough
Appendix J: Study Two Recruitment Letters to Cancer Organisations and Support Groups

I would like to introduce myself as a PhD student currently enrolled at Charles Sturt University. My research project aims to investigate the impact that cancer has on the psychological well-being of adults whose parents have cancer. It is anticipated that information gained from this study will help family members in the future to better adjust and manage issues that affect them as a result of their parent’s illness. Additionally, such information can provide valuable insight to service providers to ensure that their programs cater to the needs of this group.

At the commencement of my PhD I conducted a small interview study to determine the range of psychological outcomes that arise in adults whose parents have cancer, specifically looking to see whether positive psychological outcomes such as personal growth and enhanced relationships were possible. The interview data suggests that such outcomes are possible, however they tend to be determined by the emotional impact that the illness had on the adult child and their involvement in their parent’s care.

The next stage of my research is to investigate this area on a much larger scale. To achieve this goal I will be conducting a survey commencing in February and remaining open until 30 May 2010. I am writing to your organisation to determine whether you would be willing to inform your members of my research and encourage them to pass on the information to their adult children (aged over 18 years) to help me recruit potential participants. Information about the study can be circulated in a number of ways including:

- A paragraph or two in newsletters or flyers that you produce, OR

- Distribution of the participant Information Statement to your members inviting people to join the study, OR

- I can attend a meeting to tell your members about my research.

I have enclosed the participant Information Statement to provide you with additional information about the project. Participation in the survey is voluntary and the project has been approved by the Charles Sturt University Ethics in Human Research Committee. Research funding is available so I will pre-arrange with you to meet any costs associated with supporting this project or a suitable donation can be made to your organisation to thank you for your assistance.

Please indicate the extent to which you can assist (if at all) by completing the Indication of Project Support sheet included with this letter and return it using the reply paid envelope. If your organisation can support my project please provide the preferred contact details for the individual with whom I should liaise and I will contact them once I have received your response.

If you would like to discuss this matter with me or would like to know more about my research please do not hesitate to contact me on 0430 878 940, or via e-mail on jlevesque@csu.edu.au.

Yours Sincerely,

Janelle Levesque
B Psych (Hons)
Grad Cert in Research Management
PhD Candidate
RESEARCH INFORMATION SHEET

Investigating Parental Cancer: Psychological benefits, emotional reactions and involvement in caregiving

In an effort to increase understanding of what it is like to have a parent with cancer, and ultimately to improve the delivery of support services to family members I am seeking information and opinions from you via an anonymous questionnaire. This study is an essential component of my doctoral program and the information obtained from it will form the basis of my dissertation. This project is being supervised by Associate Professor Darryl Maybery from the Department of Rural and Indigenous Health at Monash University and Dr Phil Chittleborough from the School of Social Science and Liberal Studies at Charles Sturt University.

Aim of the research

The ultimate aim of the research is to investigate the experience of adults who have a parent with cancer, specifically looking at how they adjust to the situations they face and their level of involvement in caring for their parent. It is anticipated that information gained from this study will help family members in the future to better adjust and manage issues that affect them as a result of their parent’s illness. This research will help identify the needs of adults who are dealing with the experience of having a parent with cancer and this information could be used as the basis for support services and education for individuals experiencing similar situations.

Who can participate?

Any willing person who meets the following criteria:

- You are over 18 years of age
- You were over 18 when your mum or dad was diagnosed with cancer
- Your parent was diagnosed with cancer at least 12 months ago (i.e. before February 2009)
- If your parent passed away your loss happened at least 6 months ago (i.e. before August 2009)

What's involved?

Participation in this project is voluntary. If you agree to participate in this study please log onto the website given below and you will be able to complete the entire survey on-line. Alternatively, call 0430 878 940 or e-mail jlevesque@csu.edu.au for a copy of the questionnaire to be mailed to you. Please remember that there are no right or wrong answers – just your own reflections and opinions.

http://www.surveymonkey.com/s/parentalcancer

It is expected that the survey will take between 50 to 60 minutes to complete. If you are completing the questionnaire on-line you can chose to complete it over several sessions by saving your responses and logging in at a later time. Should you change your mind, you are free to withdraw from the research at any time without penalty or discriminatory treatment. Please note that if you submit a completed survey (either on-line or via mail) this will indicate your consent to participate in the study.
What will happen to the information I provide?
The results from this study will be used as the basis of my doctoral thesis and for future publications and presentations. Your anonymity is guaranteed as all information is submitted anonymously and therefore no identifying information can be published.

Although the data we keep is anonymous, all materials associated with the research will be kept in a locked filing cabinet or a password protected computer and destroyed five years after the research has been completed, or published.

What should I do if I become upset as a result of completing the survey?
It is hoped that participation in this project will provide you with an opportunity to offer some insight into your experience of having a parent with cancer, however the questions I am asking require you to reflect on an emotional time in your life. If at any time there is a question you do not wish to answer please leave it blank and move onto the next question.

Should you feel distressed there are several support services that are available to you. Telephone services that you may choose to call for confidential (anonymous if you wish) counselling include Lifeline (13 11 14 -24 hours) or the Cancer Council Helpline (13 11 20, 9am – 6pm Monday to Friday). Additionally, the Cancer Council in each state provides a range of services to family members. For further information please contact the Cancer Council in your state on the numbers provided below or through accessing their websites.

ACT
(02) 6257 9999
http://www.actcancer.org/

NSW
(02) 9334 1900

NT
(08) 8927 4888

QLD
(07) 3258 2200

SA
(08) 8291 4111

TAS
(03) 6233 2030

VIC
13 11 20

WA
(08) 9212 4333
http://www.cancerwa.asn.au/

NOTE: Charles Sturt University’s Ethics in Human Research Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Executive Officer:

The Executive Officer
Ethics in Human Research Committee
Academic Secretariat
Charles Sturt University
Private Mail Bag 29
Bathurst NSW 2795

Tel: (02) 6338 4628
Fax: (02) 6338 4194

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.
If you have any questions about this study please contact Janelle Levesque on 0430 878 940 or via e-mail on jlevesque@csu.edu.au or Associate Professor Darryl Maybery on 03 5128 1000.

Thank you in anticipation, your help with this study is very much appreciated.

Janelle Levesque  Assoc. Prof Darryl Maybery  Dr. Phil Chittleborough
0430 878 940  03 5128 1000  02 6051 6760
jlevesque@csu.edu.au  darryl.maybery@med.monash.edu.au  pchittleborough@csu.edu.au
Indication of Project Support

Investigating parental cancer: Psychological benefits, emotional reactions and involvement in caregiving.

Our organisation has received information about the upcoming research project titled 'Investigating parental cancer: Psychological benefits, emotional reactions and involvement in caregiving'. After considering your request for assistance in recruiting participants our response is:

☐ We are able to provide assistance by including information about your project in our newsletter/flyers.

☐ We are able to provide assistance by distributing Information Statements to our members.

☐ We request that the researcher attend a meeting to inform our members about the project.

☐ We are unable to provide assistance with your project.

Name of Organisation: ____________________________________________________________

(Please provide the name of your organisation even if you are unable to help so that follow up correspondence is not forwarded to you on this matter.)

Name of preferred contact person: ______________________________

Contact Number: _____________________________________________

E-mail address: ______________________________________________

Signed: _____________________  Date: ________________

Please print name: ________________________________________

Please return form in the Reply Paid envelope provided.
### Appendix K: List of Organisations Assisting in Recruitment for Study Two

<table>
<thead>
<tr>
<th>Nationwide Organisations</th>
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</thead>
<tbody>
<tr>
<td>Bowel Cancer Australia</td>
<td>Ovarian Cancer Australia</td>
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<tr>
<td>Breast Cancer Network Australia</td>
<td>Prostate Cancer Foundation of Australia</td>
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<tr>
<td>Dragons Abreast Australia</td>
<td>The Australian Lung Foundation Inc</td>
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<tr>
<td>Leukaemia Foundation of Australia</td>
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<tr>
<td>Melanoma Patients Australia Inc</td>
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<table>
<thead>
<tr>
<th>Australian Capital Territory (ACT)</th>
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<tbody>
<tr>
<td>Cancer Council ACT</td>
<td>OvCan</td>
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<tr>
<td>Dragons Abreast ACT</td>
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<tr>
<th>New South Wales (NSW)</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Brain Tumour Network – The Calvary Mater</td>
<td>Cancer Information &amp; Support Society</td>
</tr>
<tr>
<td>Breast Cancer Buddies</td>
<td>Cancer Support Centre</td>
</tr>
<tr>
<td>Breast Girls</td>
<td>Candles Cancer Support Group</td>
</tr>
<tr>
<td>Broken Hill Cancer Support Group</td>
<td>Carers NSW</td>
</tr>
<tr>
<td>Broken Hill Prostate Cancer Support Group</td>
<td>Carers Support Group – Kincumber</td>
</tr>
<tr>
<td>Busting with Life</td>
<td>Carers Support Group - Shellharbour</td>
</tr>
<tr>
<td>Byron Bay Breast Cancer Support Group</td>
<td>Central Coast Prostate Cancer Support Group</td>
</tr>
<tr>
<td>Camden Haven Dragon Boats</td>
<td>Cessnock Community Healthcare</td>
</tr>
<tr>
<td>Camden Survivors of Breast Cancer</td>
<td>Coffs Harbour Prostate Cancer Support Group</td>
</tr>
<tr>
<td>Can Assist Blue Mountains</td>
<td>Cooma Breast Cancer Support Group</td>
</tr>
<tr>
<td>Can Assist Guyra</td>
<td>Cooma Living with Cancer Support Group</td>
</tr>
<tr>
<td>Can Assist Lockhart</td>
<td>Cowra Breast Cancer Support Group</td>
</tr>
<tr>
<td>Can Assist Narrandera</td>
<td>Dragons Abreast Byron Bay</td>
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<tr>
<td>Can Assist Parkes</td>
<td>Dragons Abreast Dubbo</td>
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<tr>
<td>Can Assist West Wyalong</td>
<td>Dragons Abreast Wagga Wagga</td>
</tr>
<tr>
<td>Cancer Council NSW</td>
<td>Dubbo Carers of People with Cancer Support Group</td>
</tr>
<tr>
<td>Cancer Council NSW – Far North Coast</td>
<td>Dubbo Prostate Cancer Support Group</td>
</tr>
<tr>
<td>Cancer Council NSW – Gosford</td>
<td>Glenn Innes Cancer Support Group</td>
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<tr>
<td>Cancer Council NSW – Hills Hub</td>
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</table>
### New South Wales (NSW)

<table>
<thead>
<tr>
<th>Organization</th>
<th>Organization</th>
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<tbody>
<tr>
<td>Gynaecological Educational Support Group</td>
<td>Northern Rivers Evening Prostate Cancer Support Group</td>
</tr>
<tr>
<td>Hunter Prostate Cancer Alliance</td>
<td>Orange Prostate Cancer Support Group</td>
</tr>
<tr>
<td>Illawarra Cancer Support Groups</td>
<td>Pendragons Abreast</td>
</tr>
<tr>
<td>Illawarra Breast Cancer Support Group – Warilla</td>
<td>Shoalhaven Breast Cancer Support Group</td>
</tr>
<tr>
<td>Illawarra Breast Cancer Support Group Inc</td>
<td>Sydney Neuro-Oncology Group</td>
</tr>
<tr>
<td>Lourdes Hospital</td>
<td>Tamworth Carer Support Group</td>
</tr>
<tr>
<td>Lower Blue Mountains Breast Cancer Support Group</td>
<td>The Entrance Carer Support Group</td>
</tr>
<tr>
<td>Macarthur Breast &amp; General Cancer Support Group</td>
<td>The Leukaemia Foundation – Riverina/Albury/Border</td>
</tr>
<tr>
<td>Make Today Count Cancer Support Group</td>
<td>Tweed/Brunswick Breast Cancer Support Group</td>
</tr>
<tr>
<td>Matar Hospital</td>
<td>Tweed/Murwillumbah Cancer Support Group</td>
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<tr>
<td>Nepean/Blue Mountains Prostate Cancer Support Group</td>
<td>Urological Cancer Organisation</td>
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<tr>
<td>Gosford Hospital Cancer Care Centre</td>
<td>Wellington Cancer Support Group</td>
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<td>New England Carer Support Service</td>
<td>West Wyalong Ladies Cancer Support Group</td>
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<tr>
<td>NOgIN</td>
<td>Westmead Breast Cancer Institute</td>
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<td></td>
<td>Yamba Breast &amp; Other Cancer Support Group</td>
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### Northern Territory (NT)

<table>
<thead>
<tr>
<th>Organization</th>
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<tbody>
<tr>
<td>Alice Springs Prostate Cancer Support Group</td>
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<td>Darwin Prostate Cancer Support Group</td>
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### Queensland (QLD)

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<tbody>
<tr>
<td>Biggenden Bosom Buddies</td>
<td>Caloundra Breast Cancer Support Circle</td>
</tr>
<tr>
<td>Bloomhill Cancer Help</td>
<td>Cancer Partners and Family Support Group - Brisbane</td>
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<tr>
<td>Breast Cancer Association of Queensland</td>
<td>Capricorn Coast Yeppoon Prostate Cancer Support Group</td>
</tr>
<tr>
<td>Breast Friends Breast Cancer Support Group</td>
<td>Carers Queensland</td>
</tr>
<tr>
<td>Bundaberg &amp; District Prostate Cancer Support Group</td>
<td>Choices for Women Program</td>
</tr>
<tr>
<td>Queensland (QLD)</td>
<td>South Australia (SA)</td>
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<tr>
<td>CQ Prostate Cancer Support Group -</td>
<td>Barossa Area Fundraisers for Cancer</td>
</tr>
<tr>
<td>Rockhampton</td>
<td>Cancer Voices South Australia</td>
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<td>Dragons Abreast Sunshine Coast</td>
<td>Carers South Australia – Northern Country Carers</td>
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<td>Dragons Abreast Bribie Island</td>
<td>Dragons Abreast Adelaide</td>
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<td>Gladstone Prostate Cancer Support</td>
<td>Fleurieu Cancer Network</td>
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<tr>
<td>Group</td>
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<tr>
<td>Gympie &amp; District Prostate Cancer</td>
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<td>Support Group</td>
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<td>Ipswich Prostate Cancer Support</td>
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<td>Maroochydore/Sunshine Coast</td>
<td>Myeloma South Australia Support Group</td>
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<tr>
<td>Prostate Cancer Support Group</td>
<td>Royal Adelaide Hospital – Social Work &amp; Counselling</td>
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<td>Services</td>
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<td>Secondary Challenges Support Group</td>
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<td>Women’s Health Riverland Regional Health Service</td>
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### Victoria (VIC)

<table>
<thead>
<tr>
<th>Group Name</th>
<th>Group Name</th>
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<tbody>
<tr>
<td>Diamond Valley Prostate Cancer Support Group</td>
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<td>Prostate Box Hill</td>
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<td>Echuca Moama Breast Cancer Support Centre</td>
<td>Ringwood Prostate Cancer Support Group</td>
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<td>Geelong Prostate Cancer Support Group</td>
<td>Stawell Breast Cancer Support Group</td>
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<td>Goulburn Valley/McGrath Breast Care Nurse</td>
<td>Support Junction</td>
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<td>Heathcote Breast Cancer Support Group</td>
<td>The Advanced Breast Cancer Group</td>
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<tr>
<td>Inglewood &amp; Districts Cancer Support Group</td>
<td>The Peter Mac Familial Cancer Centre</td>
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<td>Life Goes On</td>
<td>The Thursday Girls</td>
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<td>Loddon Mallee Integrated Cancer Services</td>
<td>Westgate Region Prostate Cancer Support Group</td>
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<tr>
<td>Melbourne Gynaecological Cancer Support Group</td>
<td>Yaram Cancer Support</td>
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### Western Australia (WA)

<table>
<thead>
<tr>
<th>Group Name</th>
<th>Group Name</th>
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<tbody>
<tr>
<td>Amazons Perth Dragon Boat Club</td>
<td>Familial Bowel Cancer Support Group</td>
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<tr>
<td>Breast Cancer Foundation of Western Australia Inc</td>
<td>Fremantle Prostate Cancer Support Group</td>
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<tr>
<td>Cancer Council- Crawford Lodge</td>
<td>Leukaemia Foundation WA</td>
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<td>Cancer Council Western Australia</td>
<td>Women’s Cancer Support Group</td>
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<td>Dragons Abreast Crewsaders</td>
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Appendix L: Study Two Electronic Recruitment Message

Investigating Parental Cancer - Research Participants Needed

A research study investigating the effects of having a parent with cancer is about to start. The research aims to gain insight into how a diagnosis of cancer in one’s mother or father impacts on adults and their adjustment to this experience.

What's involved?
Simply complete the on-line questionnaire that is available at:

http://www.surveymonkey.com/s/parentalcancer

It is estimated that the questionnaire will take between 50-60 minutes to complete. You can save your questionnaire to complete over several sessions if you like.

Who can participate?
Any willing person (student or staff member) who meets the following criteria:

- You are over 18 years of age
- You were over 18 when your mum or dad was diagnosed with cancer
- Your parent was diagnosed with cancer at least 12 months ago (i.e. before February 2009)
- If your parent passed away your loss happened at least 6 months ago (i.e. before August 2009)

How can I get more information?
There is an information statement at the beginning of the questionnaire. You can access this statement at the website listed above, and if you decide not to continue simply log out of the screen – you do not have to complete the questionnaire.

Alternatively you can e-mail the researcher on jlevesque@csu.edu.au to obtain a copy of the information statement.

Thankyou for considering participation.